# HOME HEALTH CARE: PRESENT AND FUTURE OPTIONS

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## HEARING

BEFORE THE

SUBCOMMITTEE ON HUMAN SERVICES

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

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# HOME HEALTH CARE: PRESENT AND FUTURE OPTIONS

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MONDAY, SEPTEMBER 30, 1985

House of Representatives,
Select Committee on Aging,
Subcommittee on Human Services,
*New York, NY.*

The subcommittee met, pursuant to notice, at 9:40 a.m., in the fifth floor board room, Annenberg Building, Mount Sinai Medical Center, New York, NY, Hon. Mario Biaggi (chairman of the subcommittee) presiding.

Present: Representatives Biaggi and Manton.

Staff present: Robert B. Blancato, staff director; and Teresa S. Karamanos, deputy staff director.

## OPENING STATEMENT OF CHAIRMAN MARIO BIAGGI

Mr. Biaggi. The hearing is called to order.

Before I commence my remarks, Congressman Tom Manton will be joining us momentarily. Exercising my prerogatives as chairman, I will proceed for the purpose of getting the hearing underway and conclude and release the witnesses so they can go on their merry way.

In any event, I am delighted to convene this hearing on the Subcommittee on Human Services of the House Select Committee on the Aging which is to examine our present and future policies of providing home health care for the aged. I want to thank Dr. Robert Butler, who is no stranger to this issue, and Barbara Brenner of the Mount Sinai staff, for their assistance in bringing us here today.

The committee would also like to note the efforts of Dr. Walter Sencer who has been a tireless advocate for home care and who has been an active participant in this process.

We have known for some time that there remains an unhealthy and unacceptable reliance on institutional care. We know further that our two largest health care programs for the elderly, Medicare and Medicaid, spend a disproportionate amount of their resources on nursing home services.

Consider these facts:

Total public expenditures for nursing home care are running over $15 billion annually, supplemented by $12.3 billion in private funds;

Medicaid, by far the largest supporter of nursing home care, provides over $13 billion of this amount. This is almost 90 percent of the total Medicaid budget.

Medicare, on the other hand, spends less than 2 percent of its budget on nursing home care. Yet, only 2.4 percent of its benefits paid are for home care services.

The evidence is clear. Home health care should be the option of first resort rather than last resort. Yet, the magnitude of public and private investment in our Nation's 7,000 hospitals and 23,000 nursing homes has made this goal elusive.

Other social service programs which have the ability to provide home care services, such as the social services block grant, title III of the Older Americans Act, and the Veterans' Administration are insufficiently funded and lack categorical specificity.

For example, Federal funding for all social services provided through the block grant dwarfs the amount we spend on nursing home care by one third.

According to a recent study by the National Governors' Association, States spend two-thirds of their public funds on nursing home care and less than one-third on home health and community-based care.

The demographics threaten to worsen an already unacceptable situation.

The 5 percent of our total elderly population which now are in nursing homes can be expected to grow by 46 percent over the next 20 years, assuming constant mortality. If we assume decreasing mortality, this figure jumps by 100 percent.

In only nine States do Medicaid expenditures for home health care exceed 1 percent of the total Medicaid budget. In New York, we are the leader by accounting for 78 percent of all Medicaid home health benefits nationwide.

Today we are here to generate ideas and options for future policy discussion in Congress. There are many major areas where Congress will have to act in a comprehensive and coherent fashion if we are to assure home care as a viable method of caring for the elderly.

Prior to major revisions in Medicare and Medicaid, there are a number of steps that Congress can take to immediately ease this problem.

First, expand the home health care benefits under Medicare with existing resources through the savings generated by the DRG or prospective payment program.

Second, expand tax credits for families who care for elderly relatives at home. I have authored a bill, H.R. 955, which would provide a $500 tax credit for those families who provide home care at least one half of the year.

Third, repeal the existing penalties in the SSI Program which result in the reduction of almost one-third of benefits for a recipient who lives in the home of a family member.

Last, initiate a comprehensive, new national study conducted by the General Accounting Office and the Office of Technology Assessment which would measure the cost effectiveness of home care as compared to institutional care. Until we have an accurate assessment of the costs of these options, home care will remain an elusive option to the majority of elderly in need of such care.

In concert with these evaluations, the current administration needs to accelerate its reviews of the so-called 2176 waiver program. This progam has provided limited home and community care options for certain segments of the elderly population in States in order to test their cost.

It is time that we produce the evidence of their merit in order to give families and seniors themselves the ammunition to be the first line of defense for their needs by providing them a full range of home health care services.

I thank the witnesses for coming here today and look forward to the testimony.

Mr. **Biaggi**. I would like to recognize Barry Freedman, senior vice president of Mount Sinai Hospital.

## STATEMENT OF BARRY FREEDMAN, SENIOR VICE PRESIDENT, MOUNT SINAI MEDICAL CENTER, AND DIRECTOR, MOUNT SINAI HOSPITAL

Mr. **Freedman**. Thank you, Mr. Chairman.

Mount Sinai Medical Center is extremely pleased to be the site of today's hearing by the Subcommittee on Human Services of the House Select Committee on Aging.

In particular, we wish to acknowledge Congressman Biaggi's leadership in drawing attention to home health care, an area neglected and long overlooked in the development of Federal health care policy.

Addressing the gaps in home health care services could not be more timely in the context of rapid change in the delivery and financing of hospital care, particularly care of the elderly. Changing law and regulation, as we know, are dictating more selective admissions and shorter hospital stays.

As a tertiary care center serving many elderly and chronically ill patients, Mount Sinai is just as concerned as community health providers that a continuum of care, not just acute care, be available and accessible to the elderly.

Mount Sinai Medical Center has made a serious and long-term commitment to developing services and new knowledge to meet the needs of a rapidly aging population.

With the establishment of the Ritter Department of Geriatrics and Adult Development in 1982, under the leadership of Dr. Robert Butler, Mount Sinai became the first school of medicine to have a department of geriatrics.

Home health care is an integral component of care for elderly patients served at Mount Sinai and at our affiliates—the Jewish Home and Hospital, Elmhurst Hospital, and North General Hospital. These institutions support home health care programs for both the recently discharged patients and for patients who require long-term management in the community.

As an academic medical center, Mount Sinai takes seriously its responsibility to participate in the formulation of public policy in partnership with our elected officials.

Again, we welcome you and your invited guests and look forward to a stimulating and provocative hearing.

Mr. BIAGGI. Thank you. I hope it is stimulating. We could do with less provocation. We had an exciting enough week last week.

The first witness will be an old friend and gentleman I haven't seen since his landslide victory for council presidency of the city of New York, a man who has been committed to his concerns for the elderly. His activities, initiai activities were memorable. It required courage to buck the system, and bucking the system always invites criticism and political peril, but notwithstanding that, he went forward and his work in the nursing home scandals was outstanding and should never be forgotton, Mr. Andrew Stein.

## STATEMENT OF HON. ANDREW STEIN, BOROUGH PRESIDENT OF MANHATTAN

Mr. STEIN. Thank you, Mario.

First, I would like to thank my friend, Congressman Biaggi, for all the work he has done in this area. There are very few people in Congress who recognize the importance of home care specifically and in general, and Congressman Biaggi has been a champion of the rights and needs of senior citizens. I would like to thank him for all his patient and dedicated work.

I would like to take this opportunity to praise Mount Sinai and in particular Dr. Butler. He has truly been a leader in this field of caring for the elderly in an innovative way and his work is extremely important to the welfare of that group.

I welcome the opportunity to address the distinguished members of this congressional subcommittee on one of the most critical issues facing the Nation.

It is an issue that touches nearly everyone. Last summer I held a hearing entitled "Home Care: The Humane Option," and later issued a report of the proceedings. Almost every day since then, my office has received calls from constituents seeking help with various home care problems: A daughter-in-law seeking someone to look after her ailing mother while she works; a son-in-law anxious to bring his father-in-law home from the hospital after surgery; a wife, seeking to forestall the admission of her husband, diagnosed as having Alzheimer's disease, to a nursing home.

As medical advances increase life expectancy, and chronic illness and disability become increasingly common among the elderly; the need for home care becomes more acute. This need has been exacerbated by recent changes in the Medicare reimbursement system. Prospective payment or the "diagnosis related groups" payment system encourages hospitals to reduce the length of hospital stays for Medicare patients.

The Federal Government's cost containment strategy will certainly increase the demand for home care services. If we force elderly patients out of hospitals sooner, we must provide them with the necessary followup home care, without increasing their out-of-pocket expenses.

I have been asked to discuss policy initiatives that need to be undertaken to expand home health services. Certainly a panoply of new programs and demonstration projects will be recommended by the expert witnesses here today. I will discuss some general reforms which I believe are essential if we are to meet our obligations to our elderly citizens.

We must liberalize eligibility rules in order to make the full range of home care services available to the elderly. Currently, Medicare pays only for limited, medically oriented home care; Medicaid provides full home services, but only to the indigent. This situation has forced chronically ill elderly to make difficult and agonizing choices.

Under the Medicaid spend-down provisions, a couple must pay all costs for care until their spendable income is reduced to $567 a month. Only then will Medicaid step in. This has forced many chronically ill elderly to impoverish themselves, and their spouses, before they can receive the necessary home care assistance.

This is both cruel and shortsighted. Forced impoverishment leads to long-term reliance on public assistance and strips our elderly citizens of their dignity and independence.

Medicaid eligibility rules should be revised to reflect current economic realities. A bold step in this direction was taken recently by Judge Jeffrey H. Gallet of the Queens County Family Court. A woman sued her institutionalized husband for support, arguing that the amount of her husband's pension and social security income which she was allowed to keep under Medicaid rules was not sufficient to meet her basic needs. Judge Gallet agreed, and ruled that the woman was entitled to retain a larger share of her husband's assets.

While this ruling should be applauded, resort to support proceedings should not be necessary. Medicaid recipients, particularly home care patients, and their spouses should be permitted to retain enough of their assets so that they can meet their basic needs. In many cases, $567 a month is not enough. Failure to accept this economic fact causes unnecessary suffering, and may force premature institutionalization of many chronically ill elderly.

In addition, Medicare restrictions on home care should be modified. With the medical advances of the last two decades, its acute care bias has become outmoded. Senior citizens are living longer with debilitating illnesses such as Parkinson's, Alzheimer's, and stroke, which require long-term custodial care, not highly skilled medical care. Restrictions on such care should be eased so that treatment of these chronic conditions can take place in the home for as long as possible.

Furthermore, incentives must be found to encourage Blue Cross/Blue Shield and other private insurers to develop long-term care insurance.

It is gratifying to learn that the Fireman's Fund, Prudential, and Metropolitan Life are currently examining the feasibility of such insurance policies. It is my hope that other insurance companies will follow suit.

Ultimately, home care should be integrated into a comprehensive health care plan for the elderly. Currently, we are juggling at least five major Federal programs: Titles XVIII, XIX, and XX of the Social Security Act, title III of the Older Americans Act, and Veterans' Administration programs. Since the availability of services to any given individual depends on the financing source, it is not surprising that we are left with an unwieldy patchwork of overlapping benefits, differing restrictions and copious amounts of paperwork.

"Elderplan," the social health maintenance organization model currently in place in Brooklyn and New York City shows great promise as a way of reducing such fragmentation. In this case, the single provider organization assumes responsibility for comprehensive care of the patient under a fixed, prospectively determined budget. Enrollees pay premiums, as in an HMO—and the various Federal programs complete the financing package. I believe funds should be made available for further demonstrations incorporating the S/HMO model.

It has been said that a civilized society can be measured by its treatment of its most vulnerable—its children and its elderly. Many older Americans are now facing forced impoverishment or unwanted institutionalization. When medicare and medicaid were enacted in 1965, the elderly were promised that health care costs would not drive them into poverty. That promise has not been kept—not because of a lack of good legislative ideas, but because of a lack of political will.

I commend this committee and Congressman Biaggi on the work they have done and urge you to find a way to allow our chronically ill senior citizens to live out their lives in dignity, in their own communities.

Again I want to thank the committee and Mount Sinai for all the work that they are doing and hope that we can continue to press for alternatives to institutionalization and home care.

Thank you very much.

Mr. BIAGGI. Thank you, Andy.

Dr. Robert Butler is chairman of the Gerlad and May Ellen Ritter Department of Geriatrics and Adult Development at Mount Sinai Medical Center and a long-time advocate of the elderly. We are happy with the fact that you are happy, Dr. Butler.

## STATEMENT OF ROBERT N. BUTLER, M.D., BROOKDALE PROFESSOR OF GERIATRICS AND ADULT DEVELOPMENT; AND, CHAIRMAN, GERALD AND MAY ELLEN RITTER DEPARTMENT OF GERIATRICS AND ADULT DEVELOPMENT, MOUNT SINAI MEDICAL CENTER

Dr. BUTLER. Thank you.

It is an honor to be present before you, Mr. Chairman. I will submit my prepared statement for the record and just provide some highlights.

[The prepared statement of Dr. Butler follows:]

### PREPARED STATEMENT OF ROBERT N. BUTLER, M.D., BROOKDALE PROFESSOR OF GERIATRICS AND ADULT DEVELOPMENT; AND, CHAIRMAN OF THE GERALD AND MAY ELLEN RITTER DEPARTMENT OF GERIATRICS AND ADULT DEVELOPMENT, MOUNT SINAI MEDICAL CENTER

Mr. Chairman, I am pleased to present testimony today concerning one of the great concerns facing older persons and their families, home health care.

This country has never adopted a National Policy for Long-Term Care, where I mean both institutionalized and non-institutionalized care. We have discussed it for many years but we have not adopted a systematic, comprehensive policy or a set of policies. To do so requires a vision of the character of the problems and needs of older persons and their families and a conception of the kinds of programs that would be required to meet those needs that includes the development of basic knowledge and of well-trained personnel to carry them out. Instead, we have created a hodgepodge of programs with fragmented financial sources of support and have depended upon minimal to inadequate training of personnel.

Today is the end of the Fiscal Year 1985. Mr. Chairman, it is an appropriate day to conduct hearings to evaluate where we are at this juncture and what options lie ahead in FY 1986 and beyond.

It is also appropriate because in October 1983 this country entered upon a new system of prospective payment in our hospitals. The State of New York will become a part of that system in 3 months on January 1st 1986.

It is too early to have clear definitive studies of the consequence of the Diagnosis Related Groups (DRGs) approach but what available reports suggest a deterioration in the care of older citizens. The manner in which the DRG is constructed makes many older persons unattractive for hospital admission and leads to their rapid discharge ("sicker and quicker").

Remarkable social and health progress led to the unprecedented mass production of old age. The 85 plus age group is the most rapidly growing age group in all industrialized nations. Perhaps 75% of persons over 85 in the United States remain in reasonably good condition and are not in institutions but about 20% are in institutions and another uncertain percent require a variety of home care services. In other words, the majority of persons in their 80s continue to enjoy a reasonably high quality of life in old age but a significant minority are in trouble.

The later age groups, the 75 plus and especially 85 plus, show, therefore, multiple, complex interacting physical and psychosocial pathology. Their needs are considerable.

Here at Mount Sinai, we have gained some understanding of this through our programs. In our Coffey Ambulatory Clinic we diagnose and treat some 2500 patients a year. These patients have an average age of 81 on admission to our outpatient clinic. About 65% are women because women so dramatically outlive men. Some 55% have significant mental deterioration. All have multiple pathology. They are a dramatically underserved population from a wide social economic range and reflecting considerable racial and ethnic variability. We are struggling to acquire data concerning our patients that will add to our understanding. Through analysis and interpretation of the character of the population that will predominate in the next century, we may make a contribution.

Today, there are about 2.5 million people over 85. By the year 2040, there will be 13 million which is nearly half of the present population of older persons to give the listener some sense of the magnitude of that number, the American population of people over 65 is the equivalent in size of the entire Canadian population.

Since 1968, there has been a 13% drop in deaths from all causes, a 40% drop from deaths from stroke, and a 25% drop from deaths from heart disease. We believe there will be further improvements in mortality rates and therefore a further increase in average life expectancy. Therefore, we will simultaneously see an increasing number of healthy, vigorous elder persons and an increase in the number of those that are impaired. The spectrum of age widens.

In order to avoid unnecessary institutionalization and to maintain persons in their own homes which is their wish, we must begin to adopt well organized comprehensive home health care programs now!

As the baby boomers, the largest generation in U.S. history, approaches its old age shortly after the turn of the century, we must have in place a comprehensive home health care system. We cannot suddenly develop one overnight.

As we read the projections in the future we realize that if we do not find ways to help maintain people in their own homes, we will have in excess of 4 million people in nursing homes. In addition to the 1.3 million persons in nursing homes today, there are perhaps another million persons who live in boarding houses.

There has been the longest standing concern that the provision of home health care services for the elderly will raise national health care costs and/or national home health care costs. All of the fears of policy makers has been that if home health care benefits are made available, for example, under an expansion in Medicare, families will no longer provide support themselves but will simply depend upon the state benefit. Insofar as I am aware, this has not happened in European countries where such benefits are available. Moreover, since the majority of the 75 plus and especially the 85 plus elderly are women and a majority of them have no families—having outlived husbands and children or not have any at all—we are talking about a group who will not be subject to "family abandonment" in any case. Also the adult children of older people are themselves approaching the later years.

The adult daughters are remaining at work and, therefore, not available at home. It is necessary to realise how frequently American women in the work force are not there only out of choice but out of necessity. The "two paycheck family" has become essential for family survival.

We do not have to set up home health care services in a irrational manner. We can establish a network of geriatric assessment services in the country that provide comprehensive baselines and make it possible to monitor change. This would allow us to keep track of costs as well as changes in the psychosocial and physical conditions of patients. When the cost of care of older persons in a community reaches a certain percentage of the institutional cost in that particular area, a triggering mechanism, a circuit breaker will require reassessment by a geriatric team—physician, social worker, nurse and others. There is no doubt that a point can be reached when the care of a person in the community requires so many different resources that it is no longer cost effective. The cost could soon exceed the cost in the nursing home. In other words, there are obvious economies of scale by the provision of services within a single locus. I suggest that we move toward putting such a system in place.

Here is the State of New York we have enjoyed the "nursing homes without walls" program which make it possible to provide inhome services to many who would otherwise be in nursing homes.

Let me answer your questions. "A long standing contention is that home health care services are for the most part more cost effective than in nursing home care. How valid is that assessment? Is it more applicable for certain segments of the elderly population over others?" I respond by saying that we have to begin with a clear portrait of the kind of services we want to make available. Such services should cover the spectrum of need of a ever varied, constantly changing population of patients of middle to late later life. It is my view that it is absolutely possible, indeed essential, to set up such a system which would build upon the best existent services and facilities but at long last create a comprehensive program. This requires more of us than the establishment of financing mechanisms. It requires the development of training in geriatrics in medical, nursing and allied health schools and requires an appropriate investment in research and development that would help us to build a better mousetrap, to create through health services delivery reasearch effective interventions.

Our people want non-institutionalized as well as institutionalized care. This is not a matter of antagonism toward nursing home and homes for the aged many of which are outstanding and certainly necessary. It is a matter of providing a choice to the family and to the health provider so that we can be responsive to patients and the families of patients when they exist.

You also asked me in your letter of invitation "what impact has a DRG prospective payment system had on both demand for and quality of home health care services? What if any modification in the program should be made?" As I indicated earlier we have inadequate understanding as yet of the full impact of the DRGs but the suggested trends of the undesirable ability of older patients because of the financial incentives to the hospital to avoid admission of the multiple, complex physical and psychosocial problems of significant numbers of older persons and their rapid discharge when admitted. This clearly demands both health care services and nursing home services. In the light of what I already said this make abundantly clear the need for us to move quickly in establishing comprehensive effective long-term care policies by which I mean both non-institutional and institutional care. We cannot simply move sick patients around pointlessly from hospital to nursing home to home care.

You asked if Medicaid waivers under Section 2176 under the Budget Reconciliation Act of 1981 be extended and further what if any impact they had on expanding home health care services. As you know Section 2176 tells the Department of Health and Human Services to give state renewable waivers and providing the range of home and community based services. These services are to be available to individuals who would otherwise require institutional services. Services will be given, however, only when there is an individual plan of care. However, the state must demonstrate that their waiver proposals do not increase Medicaid costs. Epre on 46 states applied for waivers.

My answer to these questions is to repeat what I have already said. We must move into an effective comprehensive policy.

Your final question to me was "what impact would proposals to increase the copayment and the medicare for home health services have or efforts to provide these services?" We have already seen the beginnings of the impact of the Reagan Administration cutbacks on Medicare. Any increase in co-payment at this time would only serve to further hold back the development of home care programs in this country.

I have emphasized the importance of developing community-based geriatric assessment units in the United States building upon the existent health care systems. I must now call upon the establishment of more effective training programs for geriatric health care workers in this country so that we may have a well trained cadre of such workers to serve not only the older persons of our country who are in need but persons of all ages. We must begin to provide career development opportunities with payment above minimum wage in order to attract people into this field. It is essential to provide well trained people and there is a shortage of training programs which would also generate jobs. Many middle class and affluent families are willing to pay for home care of relatives, but they find it difficult to obtain well trained people.

In the United States there is an annual 125% turnover for nursing home aides this is related to the absence of preservice and inservice training, career development opportunities and decent pay. The turnover rate of home health aides is also high.

The cost of training programs are modest compared to direct payment for services.

The development of geriatrics in this country is minimal for all health providers.

The Mount Sinai School of Medicine is the first Medical School in the United States to establish a full fledged Department of Geriatrics. We celebrated the second year of our academic existence on July 1st, 1985. We have developed an academic triad—the provision of services, education, and programs in research activities. We are proud of what we have accomplished so far but we have a long way to go.

There are several obstacles to the development of geriatrics in medicine in this country. First is the lack of funds for Fellowship training which means the training of physicians who are Board eligible or have completed their Board examinations in internal medicine, family practice, psychiatry etc, Second is the lack of role models i.e. older teachers and geriatricians for medical students and residents. Third is the absence of clear career development lines including sub-specialization. Finally the character of reimbursement is adverse to geriatrics.

With regard to the later, there are ongoing debates as you know with pressures building to enhance "cognitive" payments of physicians providing time intensive evalaution and care of patients, compared to reimbursement for organ specialties as well as procedure and/or surgical activities.

On this occasion, I would like to bring to your attention that Medicare provided 2 billion in graduate medical education last year yet none of this money has been devoted directly to the support of geriatrics I regard this as ironic given the purpose of Medicare. It appears that there will be significant cutbacks in Medicare support for graduate medical education. I have called for the recoupment of part of that cutback; in short, the redirection of Medicare providing graduate medical education funds for the development of geriatrics in the United States, specifically the support of a national Geriatrics Fellowship Programs. Since medicine provides a central, indeed even controlling, role in the development of care in the United States, we must have a cadre of leaders in geriatrics to help us evolve an appropriate comprehensive care system for older people. Thus the relevance to our discussion this morning on home health care services.

It has been a pleasure and an honor to testify before you this morning. I am prepared to try answer any question.

Dr. BUTLER. This country has never, underline never, adopted an imaginative national policy for long-term care either with respect to institutionalization or for home care and it is clearly long overdue. Your hearings, in my judgment, are on target for us to begin once again to try to do something about this lack.

We must not only consider financing as important as that is, but we must have a plan, a plan that has to be based on a vision of what we want for people in their old age. I refer to each of us, not just older persons today. That vision has to depend upon a better understanding of the character of late life and of the multiple complex interacting physical and psychosocial problems that older persons face, especially the very old who are becoming the dominant in the health care system.

We must not only have that basic knowledge and understanding of aging and the maladies of older persons, but have to have properly trained personnel who really have the skill and the experience of working with older persons.

At present we have a situation of minimal to untrained people working in the care of older persons. We lack a fundamental plan of organization.

Now, in October 1983, this country entered upon a new system of prospective payment in our hospitals known as the DRG's, diagnosis related groups. This State, the State of New York, will begin to be part of that system on January 1. Yet, the reports that have come to us from around the Nation are not encouraging, reports that suggest a marked deterioration in care of the older citizens of this society, because of the multiplicity of problems, how unattractive our older persons are to the hospitals that have to deal with important economic considerations, and how attractive it is to rapidly discharge patients who are older and who may become costly in view of the fact that the DRG payment is for one diagnosis.

It is "sicker and quicker."

I suggest we have cost containment driven by economic considerations. Now this in the context of a historic occasion on which we have had an unprecedented mass production of old age, a remarkable reduction in the number of deaths, 13 percent from all deaths since 1968; 40 percent reduction in deaths from strokes since 1968, and a 25 percent reduction in deaths from heart attacks just since 1968. It is not to be overlooked that in 1965 came the passage of Medicare and Medicaid because we do believe that the increasing access of older persons to health care contributed to this remarkable reduction in deaths in the later years of life.

But in addition, we have had the contributions of research, of the antihypertensive campaign, of changes in lifestyle, curbing of tobacco intake, all of which have contributed, and now we have the 85-plus age group as the most rapidly growing age group in the United States and indeed in all industrialized nations. We have today 2.5 million people over 85.

Perhaps more staggering is to realize that we will have 13 million people over 85 in the year 2040. To give you a sense of how large that number is, we now have about 26 million people over 65, so we will have half as many over 85.

To give a sense of the magnitude, the entire populaton of Canada is equal to the number of older persons we have in the United States today.

Now, all of us know that older people and their families, to the degree possible, want older persons to remain in their own homes, but for that to happen, we have to implement a national health care program and we don't have a lot of time. The largest of American generations, the baby-boomers, not too far from now are going to reach "Golden Pond" and when they do, hopefully we will have in place a decent program because if we don't, we will have created a situation of considerable chaos.

Four million people will be in nursing homes instead of 1.3 million people in nursing homes if we don't begin to plan options to nursing home care.

I would like to take a minute to talk about some of the usual anxieties which are present among policy makers as it bears upon the introduction of a national comprehensive home care program, the kinds of anxieties which I picked up in my years in Washington within the upper echelons of the Department of Education and Welfare. One is the family abandonment concept, which is a myth. The notion is if we begin to provide home care, the family's natural efforts for their members would decline, that they would turn to the Government.

From information we have available to us from the United Kingdom, Scandanavia, from other parts of Europe, that has not happened. In fact, the American family remains the number one caretaker of its older members.

Second, we have to recognize that with the 75-plus and 85-plus age group the most rapidly growing, we must think of the age of their adult children. We are talking about people 55 and 60 already themselves beginning to develop chronic illnesses and to have problems of their own.

Mr. Biaggi. Excuse me for interrupting. I guess in the past that might be more accurate than it is today. It is my feeling that those chronic illnesses develop later than 55 and 60 given the extension of life and the quality of life, which leads to our 85 and over.

Am I right in concluding that there would be less development of chronic illnesses today in that age group than there were 20 or 25 years ago?

Dr. Butler. In a way you are right because what has happened is we have a spectrum of increasingly vigorous, healthy, productive older persons. At the other extreme we have an impressive increase in those who are impaired. In fact, throughout the totality of life, even between 10 and 20, we have a greater amount of disability today than we had 15, 20 years ago.

Mr. Biaggi. How do you account for that?

Dr. Butler. Medicated survival. A youngster has an accident on a motorcycle and might have died even 5 years ago and now remains alive. Someone has had a catastrophic hemorrhagic stroke at 39 and now remains alive. So the irony is that on the one hand, we have a triumphant increase in healthy, vigorous older persons, but at the same time, have those who are increasingly impaired.

Your point is well taken and I don't want to overstate the case in saying that adult children are impaired. They are not, but a significant number may be, and to then ask of them that they care for older parents——

Mr. Biaggi. They may find themselves in their own economic difficulties.

Dr. Butler. That is right.

The third point related to the provision of care by kin at home is that women are in the work force, some 60 percent now, and for those who think it is entirely a matter of choice, we have to recognize that frequently the two-paycheck marriage is absolutely essential for families to survive and to be able to support both ends of the life cycle in terms of education of children as well as care of older persons.

The essential message I wanted to present is that we would not be destructive to the American family by introducing a comprehensive national health program, not destructive to the American Federal Treasury by simply opening it up to wholesale raid, but as a matter of fact, by the provision of decent home health care services, we would be strengthening the American family, providing respite and making it possible for them to retain older persons at home.

A few words about the importance of developing a network of geriatric assessment units across this great land of ours. We have to rationalize the health care system and capitalize upon some of the experiments conduced in the Veterans' Administration showing that one can properly and broadly assess older patients not just medically, but socially and from the perspective of nursing and to look at them in terms of function and utilize the team approach in monitoring their needs and seeing that they are properly cared for.

This team makes it possible to introduce a kind of circuit breaker. No one is so unrealistic as to think we can provide funds for people to remain at home up to the moment of death if the number and intensity of impairments and costs became too great, but if we developed a kind of triggering, circuit-breaking mechanism that said when the costs begin to exceed, say, 60 percent of what institutional costs would be in that area, at that point the team could reassess the patient and come to grips with whether in fact it is time for the individual to enter some type of institution.

The last thing we want to do is to declare institutions unimportant, because they are very important. It is a matter of the proper utilization of them and not using them unnecessarily. I have emphasized the importance of developing community-based assessment and I have spoken about the importance of needing to have a plan. I want us now to take a moment to talk about training of people. Thinking back on my days of participating as a teacher in home health agencies and visiting nurses association, I found it commendable what they were able to do, but frequently there is very little training, preservice or inservice of either those who provide care in patients' homes or within nursing homes and there is an extraordinary turnover rate.

In fact, in nursing homes today, some estimate that the turnover rate is in excess of 125 percent per year. It is time for us to really contribute to developing a major training effort.

Mr. Biaggi. When you talk about training, you are talking about the professionals or the unskilled?

Dr. Butler. At the moment, I was talking about the unskilled. I am talking about those who work, maybe even for only brief periods of time, but nonetheless provide in-home services or work as nurses aides in nursing homes.

Mr. Biaggi. My experience has been that they have almost constant and close contact with the elderly person, and there are some terrible abuses that run rampant. We understand that for some it is there—it is the crossing of the threshold of employment and they really come in unskilled.

Dr. Butler. Yes.

Mr. Biaggi. Many are uncaring. It would seem to me that we should have, as you suggest, training, preliminary training, even higher standards, but if we do that we will require higher salaries.

Dr. **Butler**. Experience that people like Herbert Shore in Dallas, TX., Jacob Reingold in Riverdale in New York and others, in Miami, FL, has been that by providing training, preservice and inservice, and even a modest increase in income, above minimum wage, and giving those people working there a sense that there is a career line of development, there is a possibility that they can move ahead, reduce dramatically the turnover rate and the costs that are involved in providing this type of training; and as you know, compared to services, which always cost a great deal of money, training, like research, are really not, relatively speaking, as expensive and you often get a tremendous payoff.

Even if that turns out to be the initial entry for an occupation and the individual winds up working in a hospital or somewhere else, it is still part of that generation of decent jobs and of standards for people who will be working in the Nation's No. 3 industry, which is the health care industry.

So I agree with you it is a problem, but I don't think we should give up.

Mr. **Biaggi**. No, you can't give up because I think the success or failure of care depends a great deal upon the quality of personnel. I don't mean to characterize all the personnel as being uncaring, because on the most part, they are caring individuals because we are all human beings and you see the pain and discomfort on a daily basis and you like to reach out and be helpful irrespective of money. It is a question of just a natural response, but on the other side, the areas of abuse have become so pointed and so visible, the consequences so terrible, that I think it jeopardizes the whole system.

If you are telling me that you are geting reports from the Hebrew Home for the Aged, Jack Reingold and other places that find that even the preliminary training is successful, I am encouraged.

Dr. **Butler**. I think that would be a very interesting set of hearings or a hearing would be to get from various parts of the country the actual dollar experience. The very process of preservice training also gives you an opportunity to review people in the recruitment process and to see if some individuals aren't really qualified for whatever reasons for this kind of work.

Mr. **Biaggi**. What would you use as a standard to say people are not qualified?

Dr. **Butler**. I am not sure I would know ahead of time exactly how to establish that. I think you would evaluate on an individual basis, get a sense of those who seem impatient or irritable, to work with an older person who may be very impaired.

You get an opportunity to make judgments. If you just hire them off the street right into the job the opportunity for that kind of evaluation occurs only after, and after there may have been the abuses you describe.

You asked if I was referring to the professional or unskilled. About professional training, it is our great opportunity here at Mount Sinai to have created the first department of geriatrics. And we mean business in the sense of wanting to be sure that every medical student graduates with basic training in geriatrics.

We don't think it is responsible to graduate doctors that haven't had systematic training in this area, but Medicare, which provided $2 billion for graduate medical education last year, not 1 penny of that went to geriatric training. Since 1965, Medicare's support of graduate medical education has not done this.

So I think it is very important that we take a good look now that Medicare support of graduate medical education is under survey, and see how we can properly redirect funds that would appropriately be reduced, in any case, to the strong assertive evolution of geriatic medicine in this country.

Mr. BIAGGI. You make the point very interesting. I think we have shared comments on the fact that the medical schools of our country were remiss. The fact of the matter is, until a short time ago I think we may have had only one chair of geriatics in our country as contrasted to those overseas, smaller countries who have had several.

Now they have increased, and you are operating one, and I am delighted to know that Mount Sinai is doing it, and the medical school; but that is only one.

We need all the medical schools, given the increased numbers of the elderly. They will be a principal medical problem.

Dr. BUTLER. That is correct.

Mr. BIAGGI. In health care, no question about it. On the other side of that, to suggest Medicare for training, there are many people in the elderly advocacy groups who say Medicare dollars should only be used for Medicare benefits for the elderly; so you will have a split there.

Dr. BUTLER. I don't think there will be a split. In anything through the utilization of medical dollars, which up to now have gone for graduate medical education to be addressed to graduate medical education for geriatrics, which would be quite different and $2 billion is a substantial amount of money. With the cutbacks anticipated of up to 25 percent, a contribution of even $100 million a year to the support of geriatrics would be an incredible step forward in this country, and would help make it possible for us to play a little bit of catchup football with the United Kingdom, Scandinavia, and other countries.

I wanted to emphasize, not only the importance of your hearings in stressing the need finally to move toward home care and the importance of financing whether it is through Medicare part C, or through a combination with the private sector, with insurance companies or other approaches, but we must also be certain that the quality of those services, the way in which they are organized, the training of the people that provide them is also important.

It cannot simply be a matter of financing where we will be repeating what happened with the passage of Medicare in 1965; that is the development of an important financial system and benefit, but without the provision of adequately trained people and new ways of delivering services to older persons.

Mr. BIAGGI. With relation to the hearing, this is just—well, we are looking at it again; if you will recall, we have done this before, and periodically we commence a new initiative. This is the hearing that will close 1985, but we are underway again.

I think the real problem is making a case that home care is more effective than institutional care, and a national study should be conducted, a very serious comprehensive one.

In that connection, how would you suggest such a study be made and what should we be looking for?

Dr. **Butler**. We need a study but we have to accept the fact that at a certain point in time an individual's degree and complexity of illness may require so much in the way of in-home services that it really would not be economically feasible nor human to expect such a situation to exist within, say, a particular household. That is where the importance of the institution comes into focus.

I think we need in such a study to have a kind of triggering mechanism, something that identifies the point in which the economics on the one hand, and the amount of physical and psychosocial problems on the other, leads to an evaluation of the character of such a patient and the cost effectiveness of delivery of such care.

Mr. **Biaggi**. I would like to, at this time, introduce my colleague and a valued member of the Aging Committee, Congressman Tom Manton.

We know you have come all the way from that alien borough of Queens. Tom and I were up rather late last night at some function honoring Father John Pulose, and we talked about being here.

Tom, would you like to comment?

## STATEMENT OF REPRESENTATIVE THOMAS J. MANTON

Mr. **Manton**. Just briefly.

I would like to reaffirm that it was a late night, but a good one, and honoring a fine human being, a lot of late speeches.

It is a great pleasure to be here; and I would like to compliment the institution of Mount Sinai for having an enlightened approach to the subject of older people and for establishing this great program that you head up. I have had some earlier experiences with Mount Sinai, even though I am from the alien borough of Queens. I have had a couple of children born in this institution, and my father had a couple of very successful major operations here. So, I have very kindly thoughts toward the institution. And we are very pleased that you have this program.

When I was at city hall prior to going to Congress, there was a time when the home attendant, or home care person was an independent contractor. I think, if I recall, that was changed, and they are now employees of the voluntary institutions that contract to provide these services for the city. All of this seeming to lead toward the more orderly and professional approach.

Are there other things that you are going to professionalize these people, who for the most part, were minimum wage or perhaps are minimum wage people with limited education?

What programs, and I apologize if you already answered that, are ongoing to upgrade their skills and professionalism?

Dr. **Butler**. I think Roberta Spohn, or the representative of the visiting nurse association would be a more appropriate respondent to that.

Mr. **Manton**. I will hold that question and give the time back to the chairman.

Mr. BIAGGI. You mentioned the question of New York coming to DRG in January 1. I also characterized DRG as sicker and quicker.

We have heard such comments and you heard some reports in that regard.

How substantial are those comments?

Dr. BUTLER. I haven't had a chance to read the staff report of the Senate Committee on Aging announced in the New York Times, on either Thursday or Friday, of last week, but the reports are not exaggerated, but are a very serious reflection of what is happening in many parts of the country.

There is also the study that emanates from the Johns Hopkins University School of Public Health related to what is called the severity index which is a way of describing the fact that as we get older we have many diseases and are on many medications and have many social and personal problems, and if we don't have a system providing payment that takes that multiplicity and complexity into account, then we are damaging both the hospital and the patients.

The hospital, you can undersand, has to survive, and the patient, certainly, has to survive; so you have a doubly important situation to evaluate. We can't continue, and none of us want to continue with anything that isn't proper for the proper care of older people.

Mr. BIAGGI. Given that background and the fact that we will be changing January 1, what would you suggest to make the transition smoother and more effective?

I think this would be the time to prepare for it.

Dr. BUTLER. Well, that is right; and I think among the kinds of things that have to be done, many hospitals in New York State, I am sure are doing, and that is beginning to get proper files from within their already existent patient data sets as to how DRG will affect them, and such information must be created in terms of a study that will give us some differences between urban communities, like New York, or rural communities of New York State, so that we have a better idea.

And by having that all in place we can begin some months later to take a look and see if, in fact, in New York there are evidences of any kind of deterioration, such as exclusion at the gate, or more rapid discharge.

The reason I said your hearing is so timely is that if we do preclude people from admission, or do too speedily move them out of hospitals, then we definitely are going to have to have a major increase in home care support, and also an upgrading of nursing homes, because nursing homes may wind up with patients who are sicker and older than they have traditionally been in a position to handle.

So, I think this is a time to study it to see what the baseline is right now, and to have a monitoring system in place so we can see what happens over the next months after January 1.

Mr. BIAGGI. We plan to have a hearing on this whole transition before the end of 1985, and any comments that you might have we would appreciate, because it is critical. Because DRG is serving its purpose as far as costs are concerned; but on the other side of it no one ever contended that it was a perfect system, so let's try to ameliorate the difficulties.

You made reference to national health care as a desirable goal, and I couldn't agree with you more, but I have to make a comment so that we can get our mind in focus. There was a period not too many years ago that national health care was on the front burner, and you had a conflict between catastrophic and cradle to the grave.

Cradle to the grave clearly would be desirable. It was not politically practical, but there are those who were the advocates of cradle to grave who would not relinquish or diminish their position or compromise.

Catastrophic was doable, but because of the square option of—or the strong support for both schools of thought we just lost the opportunity. My experience from a very practical perspective, given years of observing legislative developments, is you get your foot in the door and then you see an evolution.

In every one of the good programs we have today, catastrophic would have been a very substantial step forward.

The family would be saving money over the years, a nest egg for rainy days, as the saying went. One major illness can wipe you out.

Well, you know, if we could have put that in place it would have been a very substantial step forward and then we could have built upon it. I know some of the purests will disagree with me, and they can disagree with me so long as they like, but unless they become realistic we will have nothing.

I don't know. Perhaps we will see comprehensive health care as we would like it. We point to other countries as examples. They have it in place, and we have nothing. So let's get the first step first.

It certainly is not appropriate when you are dealing with a $250 billion budget deficit. If we have a tax increase we are not going to meet that deficit by reducing spending because the pressures are too strong.

There are many interested parties out there. I think in the end it will require an increase in taxes, and Stockman suggested a 2-percent tax on the gross national product would raise $100 billion.

If we get ourselves somewhere in a reasonable area with respect to the budget we can then start talking about comprehensive health care again. Right now it is just something we talk about in academia.

Dr. BUTLER. Three points. When you survey the American public you find a tremendous interest in health care which is on your side.

No. 2, door, we have a foot in the door in medical care, and it could be reformed in some fundamental ways without any new dollars put into the system.

The reality is that we have a system which is oriented toward institutions, toward acute care, and the truth is that our population is aging and moving more and more to chronic care and to needs in the community which should be community based.

A rational cost-effective system without any new dollars put into it could begin to emerge even now.

A third point: Part of the way to build that reform of Medicare, which is essentially whether we ultimately have a vision of national health care or don't, would be to start with those over 80, with people whom no one can say don't need help.

And certainly no one could possibly say they ought to be able to take care of themselves. It is the fastest growing group, and not so huge that it is not manageable and could begin to give us experience that we could build upon so we could move stepwise, say we have learned something from the 80-plus age group, now we will move to 75 to 80, and we could begin to reshape health care for older people in this country.

Mr. BIAGGI. I am sure you will recall our frail elderly report and hearing a number of years ago. Clearly that is an area that becomes even more important when you consider the increased number of those living 85 or more. No one questions that.

I can foresee, I am not sure whether it will be implemented, but some thought will be given to making delineations in age groups. We have a similar problem in Medicare with relation to financing and maybe it will be addressed in this Congress.

If not, it will be the 100th Congress, but it must be addressed, so that expanding it, I think, will require more dollars. But, yes, we know that is in place, but you are dealing with schools of thought, people are wedded to certain notions, for whatever reason, maybe internal consumption, or maybe they just have a belief in a certain approach, who must be made to understand that in this whole process we all have the same objective, but there are many ways to heaven.

Dr. BUTLER. The other thing that is so exciting is that we have had this incredible gain in life expectancy in less than a century, 25 years, and we should be proud of that and building upon that. For example, there are other sources of revenue that could make a difference.

In the State of Arizona, excise taxes on tobacco and alcohol help to finance the health care system. It has implications in terms of health prevention to move in that direction.

We are interested in keeping the cigarette tax up to 16 cents a pack so there are sources of revenue and possible redirections within dollars already spent. It simply would change things.

Not all my many colleagues would appreciate my saying this, but there are differences in reimbursements with regard to specific organ specialities, procedures which run counter to the kind of broad assessment that is required in dealing with people as people and their total function, which is more expressive and characteristic of geriatrics, internal medicine, and so forth.

There are shifts underway both in the American Society of Surgery and the Institute of Medicine and in the House Ways and Means and the Senate Finance Committee of how to shift reimbursement—not new dollars, but ways of reforming from within.

It is a dramatic, positive change in demography, and we have to begin to respond by altering our mechanisms of finance and delivery of care.

Mr. BIAGGI. You mentioned the cigarette tax. We have legislation of increasing the cigarette tax from 16 to 32 cents and those funds to go into Medicare.

This 16 cents is supposed to run out this year and now they are trying to eliminate it. There is a fight in the Senate on that score.

It should be increased given the nature of the product that is being taxes.

Dr. BUTLER. And the adverse impact on health care dollars.

Mr. BIAGGI. Clearly. That followed. But we are mindful that nothing comes easy. Nothing comes easy.

I have made some suggestions, I wondered if you would comment on them?.

I think I said it in my opening statement, expanded coverage for home health care, Medicare as a result of the savings with DRG's.

Dr. BUTLER. I think it is a terrific idea and it relates very much to what I was saying earlier, if we are going to exclude people at the gate or discharge them prematurely, and we don't have in place better financed, and organized home care on the one hand, and institutional care on the other, we are creating an additional problem for older people and their families, so I think the use of any DRG savings to put them in those two directions would be ideal.

Mr. BIAGGI. Do you see opposition coming from the institutions?

Dr. BUTLER. No—you mean from hospitals specifically, rather than from nursing homes?

Mr. BIAGGI. Nursing homes.

Dr. BUTLER. I can't speak for nursing homes; but I would think more and more they recognize the possibility that they themselves are going to have to become multiservice institutions, that they themselves are going to have to be thinking about home care, or linking up with organizations that do provide home care, and that we are going to have to get away from the separate islands and create an integration, because as we grow older we may have many needs, from health prevention all the way to a need for an institution.

So I would think thoughtful people reflecting both sectarian homes for the aged and nursing homes, would be very positive to your suggestion.

Mr. BIAGGI. They shouldn't feel their existence is threatened?

Dr. BUTLER. I would think not. They may be troubled the other way around. The DRG's will suddenly mean that they will have a heavier load and that anything to help reduce the load would be helpful to them. You should ask representatives of that industry.

Mr. BIAGGI. What about expanded tax credits for persons caring for elderly in their homes?

Dr. BUTLER. I favor that. However, I have always worried whether it comes to tax credits for the poor, that is for those people with no taxes to pay and therefore a tax credit is not too useful.

In Japan there have been family payments which have been used, and they have a deficit problem there too.

So it may be a combination of tax credits for the middle class and beyond and some form of direct allowance for families that aren't fortunate enough to pay taxes, that might be an appropriate addendum to your proposal.

Mr. BIAGGI. Currently there is a one-third reduction in the payment of SSI for those who live with their relatives.

What about repealing that?

Dr. BUTLER. I agree with you. It is just punitive.

We don't want to discourage families from providing support, we want to encourage them, and I think this would help. Your suggestion would help greatly to strengthen the family and to maintain as an honorable and appropriate managing function in the care of older persons.

Mr. BIAGGI. Tom.

Mr. MANTON. No questions, Mr. Chairman.

Mr. BIAGGI. Thank you very much, Doctor. You have been quite helpful.

Mr. BIAGGI. Roberta R. Spohn, deputy commissioner, New York City Department for the Aging.

Nice to see you again.

Robert O'Connell, deputy director for Program Development and Evaluation, New York State Office for the Aged.

Roberta?

## STATEMENT OF ROBERTA R. SPOHN, DEPUTY COMMISSIONER, NEW YORK CITY DEPARTMENT FOR THE AGING

Ms. SPOHN. Thank you for holding this hearing. It has been most provocative so far. I am tempted to not read my testimony, but respond to your questions and the prior testimony

I am greatly concerned about suggestions to establish arbitrary age requirements for publicly funded in home services on the Older Americans Act. In the city of New York here is the same enormous growth of the very old, as the rest of the country, but we are also experiencing an enormous growth in the minority aging. In 1970, when the Department for the Aging did a study of older people living in the community we discovered then that the Hispanic elderly, who are our youngest aged were as functionally disabled as the white elderly over 80. Therefore, if we design programs on the basis of age related, rather than functional disability we will exclude a population in need.

Mr. BIAGGI. How do you account for that?

Ms. SPOHN. If your life experience is one of poverty and poor nutrition; where you have had to struggle to support your families; where you have had many children, then as a group you are going to have early and severe chronic illness.

Therefore, if we set arbitrary age restrictions on home care and other social programs, we will exclude from care those populations whose chronological age is not a predicter of need.

We should be looking for appropriate humane care.

As we move into the future, even with the economic realities concerned with deficit reduction, we must be guided by the goal of providing appropriate service depending on need.

We must also devise methods of assessing need which does not erase the humanity of the client. We cannot base our decisions on instruments which reduce human beings to numbers.

Numerical scores cannot totally predict the need for service. So as we move into the future, I would hope that assessments include a dimension which measures the human capacity of the individual, the environment in which they live, their drive for independence. as well as their perceived ability to cope. I should like to return to my written testimony

Both as a provider of services through our support of a community-based network of home care and home-delivered meals programs and as an advocate for the elderly of New York City, our department is in a unique position to observe and document the growing need for an extended range of home care services for the elderly. By home care services, I refer to a spectrum of ongoing assistances which includes not only home health care but also those essential arenas of help with house-keeping and personal care, home delivered meals and transportation needs which makes it possible to maintain residence in one's own home.

The department itself supports a broad range of services to help maintain the independence of older persons in their communities. Among these are a group of services which can be considered as part of the continuum of home care services in that they are directed to helping persons with chronic physical, functional, or mental impairment who require ongoing assistance in order to remain in their own homes and to continue to participate in family and community life. We provide housekeeping, homemaking, and personal care services to approximately 11,000 elderly annually through direct and contracted service programs. Each day home delivered meals, a vital component of home care, are served to 8,000 frail women and men who cannot shop or prepare their own meals and have no one to do so for them. In addition to these in-home services, through our Alzheimer's resource center, our field offices in each of the five boroughs of the city and through our central information and referral service we also assist the aged and their families in obtaining the home health care and long-term care services that the department does not provide. Last year over 400,000 requests for information concerning a variety of needs came to our central information and referral and our subcontractors. Home care needs accounted for a high proportion of these requests for assistance.

It is from the vantage point of both provider and planner of aging services that we offer our observations to this hearing.

First let me comment on the changes we have been following in our New York City population which are paralleled and reflected throughout the country. We have seen in the past decade a stunning increase in absolute numbers of the very old, frail elderly—those over 75 years of age who are more likely to experience health conditions and functional limitations associated with multiple chronic illness and thus require assistance. Our population 75 and over, which had increased by 18.4 percent between 1970 and 1980 has increased by another 50,000 from 381,213 in 1980 to 433,251 in 1985 according to New York State Department of Commerce population projections. Even more dramatic has been the increase in the very, very old—those above 85 years. This group grew 37 percent in the decade between 1970 and 1980 to 77,332 and are estimated to total 102,299 now—a 32-percent increase. Moreover, by 1990 it is estimated that the oldest sectors of our population—New Yorkers living into their eighties and nineties will total 127,748. While increased age brings with it greater likelihook of needing the skilled care of a nursing home, even among those 85 and above only 20 percent are in long-term care institutions. The fact is that the large majority of these frail elderly wish to remain in their own homes in the community and can do so if they have some assistance available to them.

However, while advanced age contributes to greater likelihood of needing home care, it is not only the very old who need this help. There are also younger groups of elderly in New York City whose special circumstances contribute to a relatively greater need than age alone would indicate. This is especially true for minority elderly and for older adults who live alone.

As of 1980, nearly one out of every five persons 60 years and older was a member of a minority group. Disproportionate numbers of them bring to their older years a history of poor health and a life-time of low income. Although younger than their nonminority counterparts in New York City, black, Asian, and Hispanic elderly tend to experience a greater number of chronic illnesses and associate functional impairments. And where once these elderly were more likely to live with younger family members, we have seen increasing rates of living alone among them.

Indeed, nearly one-third of New York's older adults live alone. Many are women who are also burdened by low income and poorer health. Although family members still tend to be available for some in-home care, they may not be able to provide the frequency and intensity of assistance that is needed for long periods of time. Moreover, many elderly who live alone have no family support and must rely upon community agencies to provide this care.

In a population of 1.3 million persons 60 years of age and older, the increase in the numbers of elderly who live alone, minority elderly, and the very old translates into a sharply growing need for in-home services. As a department committed to improving the quality of life for older New Yorkers by acting as their advocate and by promoting and supporting the development of a wide variety of accessible and appropriate services for them, our concerns about home health care are threefold:

The availability of home care services to all in need;

The assurance of an approprite level of home care services; and

The costs of providing services to the growing number of persons who require a range of in-home services.

I would like to comment on each of these points.

First, on the availability of home care services. New York City residents are fortunate to have an array of home care programs. I have already mentioned those supported by our department. In addition, through the New York City Human Resource Administration [HRA] 38,000 clients receive Medicaid-supported home attendant services. There are also currently 37 certified home health care agencies in New York City which provide more medically oriented home health care, most of it reimbursed under Medicare. With the certification of a limited number of proprietary agencies in New York State more agencies will become eligible to provide reimbursable home care services, thus extending the availability of medically oriented home care services.

In spite of this array of programs, however, significant gaps in home care continue to exist. This is due primarily to the fact that eligibility requirements for both Medicare and Medicaid funded programs severely limit the availability of services. As you know, Medicare reimburses only home health care and then only if it is physician authorized, skilled nursing related health care for the homebound. This very narrow scope of home care neglects the needs of those elderly with persistent chronic illness who need ongoing supportive and therapeutic service with no more than minimal medical or nursing supervision. In addition, thousands of elderly are excluded from the Medicaid supported Home Attendant Program because their income and/or assets are too great for them to be eligible for Medicaid. We estimate that there are upwards of 50,000 elderly 75 and over in New York City in this marginal income group who may be in need of some in-home assistance yet lack the financial resources to pay for this care themselves.

Our programs, funded by the Older Americans Act and New York State's Communtiy Services for the Elderly are the only publicly funded services available to the tens of thousands of elderly who are neither poor enough for Medicaid or affluent enough to purchase services privately. Yet, you know well that our funding is not only limited but has been at a standstill for several years.

Unmet need for home care services has been identified by the department in a recent survey of our home-delivered meals, housekeeping, and homemaking programs. Nearly 70 percent of homemaking programs surveyed had waiting lists. More than one-half of the home-delivered meals and housekeeping program had lists of those waiting for service. Program director reported that they were not able to provide service to all persons who have requested them. Neither are they able to meet the need for more hours of service or for a higher level of service, for example, personal care services in addition to housekeeping. Limits of service capacity imposed by current funding of these programs constrain the ability of the department to meet the growing demand for in-home services.

Our second major concern builds upon the issue of appropriateness of home care services. Data collected by the department on the elderly who use our in-home and home-delivered meal programs indicate that services provided through these programs cannot always be as extensive as clients needs required. Too often we find—as do other agencies—that clients receive the services that can be provided and not necessarily those they need. Ten percent of our program directors reported that in many cases the deteriorating condition of those elderly currently served had brought about a need for more hours of service or for a higher level of service, for example a need for assistance with personal care such as bathing, dressing, and mobility in addition to housekeeping.

We have also found that recipients of our home-delivered meals are vastly more impaired than the criteria developed by the department for service eligibility. A recent survey of these clients made for us by the Louis Harris organization indicated that functional impairment is pervasive among these men and women and for the large majority, it appears that minimal physical mobility is accomplished with difficulty, if at all. In addition to be unable to prepare meals, shop for groceries, or go outdoors, many more were found to be so incapacitated that they are unable to perform other activities of daily life such as getting out of bed, getting to the bathroom, or bathing without the assistance of another person. In many cases assistance received from informal supports is not adequate to meet these extensive needs—or there is no family member who can provide this help. Not only is the independence and dignity of these older women and men at stake: They are at increased risk of dangerous falls, mismanagement of medication, social isolation leading to depression, and lack of necessary physical exercise vital to continued well being. While we are gratified at being able to provide them with home-delivered meals, we are very much concerned with our inability to ensure that other needed services cannot be made available and thus, these men and women must make do with only a bare minimum of what is required.

There is no question but that there is a need for an enormous increase in support services for the homebound elderly. The national allocation for IIIB services under the Older Americans Act is less than that spent in New York City on the Home Attendant Program. However, it would not be efficient to turn home-delivered meals programs into the direct deliverers of supportive services. We believe that area agencies should continue to have the responsibility for assessing service needs and for determining what appropriate services should be delivered.

Given these observations of increasing unmet need for home care services among New York City's elderly, questions of cost become paramount. While it is evident from our programs that home care services can maintain a more severely impaired population at home, thus avoiding the costs—and the loss of independence associated with institutional long-term care, we must begin to acknowledge however, that shifting from institutional to home care services is not going to guarantee an overall reduction in service costs. One look at the demographics should be sufficient to convince us that we can only face expanded need for services. However, we certainly can, and must, focus our efforts on the cost effectiveness of services, that is to ensure the provision of services appropriate to an individual's needs. One of the most important findings of our recently completed home care project, which was funded by AOA and HCFA and granted Medicare waivers, was that by having help at home available, hospital stay could be shortened significantly, thus reducing costs of acute care.

This project also demonstrated that an extremely impaired older population could be maintained in the community with a package of no more than 20 hours a week of home care services when a strong informal support system was also available.

In the search for alternatives to institutionalization and the need to more effectively target community-based long-term care services, it is essential that adequate funding be available for a spectrum of home care services for all elderly so that appropriate services can be provided for all levels of need not only the most intensive and expensive needs.

Although New York State is not yet operating under the DRG system—it will go into effect January 1986—the State has had a cost containment program based on prospective payment for several years which has had a direct impact on both the Home Attendant Program and our DFTA home care services. Indeed, we have had to fund the American Red Cross to provide emergency services to older people who were being discharged from hospitals on evenings and weekends and no home support to turn to. In other instances, the lack of home supports has kept older people in hospitals for such long periods that they have lost housing and we have, therefore, had to establish a shelter program for them on discharge.

As DRG's are implemented, ensuring a sufficient base of home care services will be critical inasmuch as we can expect these conditions to intensify. Several trends in health care delivery have already begun to push hospitals to discharge person earlier. We anticiapte that in New York City these trends in hospital care will converge ot put increasing pressure upon hospitals to refuse what were once considered social admission that is, persons admitted to hospitals of a crisis in social circumstances rather than in medical conditions and to discharge people back into the community in a more timely manner. We anticipate that in addition to being asked to provide in-home services and home-delivered meals to greater numbers of elderly our programs will also be called upon to assist the elderly and their families in negotiating the complicated entitlement systems for Medicaid and Medicare and to arrange service packages where existing medical home care services do not extend far enough to provide adequate levels of service.

With changes in the health care system and growing restrictions on home health care to tighten up reimbursement, there is great concern that public agencies will be faced more and more with increased numbers of hard-to-serve clients who need home health care or even a lower level of home care which will not be reimbursable.

Anticipating these pressures and concerned with the maze of programs, eligibility criteria, and access points for service, we in New York City have already begun one effort addressed to the improved coordination of public funded home care services.

Under mayoral aegis, we have convened as an intedepartmental committee representing five agencies—ourselves, HRA, the Health and Hospital Corp., the department of mental health, retardation and alcoholism services and the department of city planning—to examine our services and service delivery in light of population changes in order to avoid duplication of effort, to interact more efficiently on behalf of clients so that services provided to clients will be both appropriate and cost effective.

The first priority issue that emerged from our interdepartmental committee was the inability under present restrictions of home attendants to assist with medications even at the level of handing someone a pill. Those backed up in our hospitals are mostly individuals with no family or friends who, if they were available, could perform this task. Perhaps one of the first steps that must be taken is to examine arbitrary and restrictive limitations that exist in current law or regulations.

However, local efforts, though essential, cannot meet the growing needs for home care. These needs are national in scope—not specific to an area, a region, or a State. They are beyond the capacity of State and local governments to serve adequately. Expanded support for a spectrum of home care services ranging from home health care to chore services must be given by the Federal Government. It is ironic that we, as a nation, are willing to spend huge sums on institutional care but so far have been unwilling to support services that not only permit older people to remain in their homes with dignity but are also appropriate to their levels of needs.

Mr. **Biaggi**. With the advent of careerists of your gender you are being afflicted with the same thing that the male population has been having over the years, so there will be a narrowing of the gap.

Ms. **Spohn**. I have been telling my daughters that I expect them to take care of me in my old age, but maybe we will change the patterns and let you men retire earlier and take care of your older mothers and fathers.

But all of these factors, the increasing number of minority elderly, the increasing numbers of old people, and the increasing numbers of people living alone are going to require changes in the system.

I was very impressed with the suggestions you made concerning using DRG savings for home care, but I would be cautious about creating a heavily medicalized system of home care.

Frail older people primarily need help to remain in their homes. While some require home health aides, we have found that home-delivered meals with housekeeping and personal care can sustain even very frail aged. They need someone to shop, to get them out of the house, provide door-to-door transportation, to scrub the floor, and to change the sheets.

Home health is only one part of what is needed. The enormous needs are for these kinds of services I described that will maintain people in the home as they get older.

As to your question as to fees for service; I personally believe that most people want to pay for the services if they can afford them. However, the ability to pay for the proper level of care is limited.

I am also concerned with the tremedous concern with the cost of home care when we show relatively little concern with the cost of catastrophic care. We require extensive assessment before we turn on home care, and yet if I were terminally ill with cancer nobody would question my physician if he ordered $200,000 worth of care and treatment. If a frail older person needs $10,000 a year for 10 years of home care, we will have to set up assessments. The precise systems which put people under a microscope and require a doctor, a public health nurse, and a social worker to determine the number of hours of care needed.

On the other hand, the province of the doctor is still supreme in determining medical care and treatment.

Mr. **Biaggi**. Except the recommendation is for second and third opinions. That has kind of come forth. I don't know how many people are seeking it, but I think there has been a substantial increase in that.

Ms. **Spohn**. I am not saying that those $100,000 bills are not proper. Even the second or third opinion about a heart bypass will be made, and on the basis of medical need the cost would be irrelevent.

Mr. **Biaggi**. If you want to make an analogy, I don't think it is on point, except that you are not questioning the validity of the surgery, of the procedure.

Ms. **Spohn**. No, that is what I mean.

Mr. BIAGGI. On the other side, you have a right to question whether an individual is entitled to 10,000 dollars' worth of care, because we have found that that is an area of abuse. Now, once it is determined that the care is required, then it should be provided as is the surgery.

Once it is determined that the surgery is required then it should be provided. So, I think that there is nothing wrong——

Ms. SPOHN. I am not sure what you mean by abuse. If you would see what an older person goes through before they get a home attendant, before they prove their medical eligibility.

Mr. BIAGGI. I don't think they should be dehumanized. But I think certainly there should be some monitoring device.

Ms. SPOHN. Absolutely; and there should be assessment. But I am saying the level at which we do this is so intense that I would suggest that there is rather little abuse of—I would say you would have a hard time finding any of those 38,000 people who didn't need that home attendant.

I would be shocked if we were to go in and find any substantial number of our home-delivered meals clients who did not need the service. I think unfortunatley with our scarcity, if anything, I could double or triple the amount, and just begin to meet the needs.

May I say that you should be very proud of is that under the Older Americans Act our legal services have been in the forefront of securing rights and entitlements to older persons who have had to fight for their services and benefits.

Mr. BIAGGI. I think we had something to do with that.

Ms. SPOHN. You should be congratulated because people forget how important those legal services have been in establishing new precedents.

The Older Americans Act has also permitted the area agencies to reach out and provide home care with community resources.

Mr. BIAGGI. We are working with the area networks all over the country, probably one of the most effective networks in our Nation.

Ms. SPOHN. They have indeed been able to put together programs by reaching out to the community; but the fact remains, there is only so much that neighbors and family can do. At a certain point you really have to pay for services.

You can not depend upon neighbors, when persons need help daily with walking, bathing and food preparation. It is an illusion that the voluntary sector will be able to provide enough care to keep very frail people in their own home.

I would like to return to the questions about who should receive care.

As you know, the Department received a HCFA-AOA grant to provide up to 20 hours of home care, case management, and other services to 400 clients by 4 different types of service organization.

Our clients were much sicker than we had assumed, yet they could be maintained with up to 20 hours of care. Many of the clients were couples where the husband was very weak and dependent. Single individuals, usually women, who were as frail end up in institutions.

We learned that you can sustain very sick and disabled people in the home when there is an elderly wife, or children, and 20 hours a week of assistance.

Our study found that there was a significant decrease in the length of hospital stay when hospitalization occurred. It appears that case management, which followed the patient into the hospital, insured the immediate provision of home care services when the patient was ready for discharge.

There were other results which were intriguing and require more study.

We had four different types of sponsors—medical on community based. It appears to us that it is the prior work experience of the director rather than the type of organization or professional training which determined the level of service and the type of clients. Directors who had worked in community services accepted sicker clients and prescribed fewer hours of care. People with prior experience in the formal health care system tended to take less sick people and give them more care. It is something to think about.

The conventional wisdom is true that older people are independent and they do not want more help than they need. As a matter of fact, they often reject help.

This is a group who never had maids, who are uncomfortable with strangers around the house. We have discovered that you can keep very disabled people at home with rather minimal care if you prepare worker and clients and pay for the care.

In closing, we do not anticipate that the implementation of the DRG system is going to cause major changes, because, we have been a cost-containment State for several years. We will watch carefully for any adverse impact patients.

The department has been funding the American Red Cross to provide emergency services to older people who are discharged from hospitals on evenings and weekends. We have already established shelters for older people, many of whom lost their homes during hospitalization. We will see if demand for this service increases. The city has also improved its coordination of home care services. Under mayoral aegis a task force on long-term care has been established to insure expedition of services.

We want to eliminate hospital overstays due to Medicaid delays in processing. Interagency cooperation can achieve some changes, but a restrictive standards concerning what level of worker can administer medications and treatment require changes by State legislation.

We have untold numbers of patients who, if there were a wife or a friend to give them an injection of insulin, without pay, could be discharged from the hospital. But since a home attendant, no matter what level of training, is not permitted to assume those functions, patients remain in the hospitals.

While the city and the State of New York have both been generous in expanding home care under Medicare, the Medicare or some other social insurance mechanism.

I agree with you on the SSI spend down. This is both a national and state problem where State supplement is reduced to $8 a month. We go further than the feds in penalizing people who live with others.

I have some concern about the tax credits as a method of increasing family support. The studies we reviewed suggest that it is lack services, rather than the financial burden which contributes to institutionalization. There is also the benefit by people who are too poor to pay taxes.

I don't know whether we need any more studies of the effectiveness of home care before we design a rational program. The studies have demonstrated that it is overwhelmingly humane, which I care first and foremost, and in all likelihood, cost-effective. It may be cheaper in some cases to institutionalize, but that should still be the last choice. We have enough information to design a system to pay for home care. I also believe that this generous Nation will support additional taxes to expand the Medicare or some other system to insure long-term care.

Thank you.

Ms. SPOHN. By the way I will pay 32 cents because I am really a smoker.

Mr. BIAGGI. I am not so sure how many smokers would discontinue.

Ms. SPOHN. None, but we will pay more. I am willing.

Mr. BIAGGI. Mr. O'Connell.

## STATEMENT OF ROBERT O'CONNELL, DEPUTY DIRECTOR, PROGRAM DEVELOPMENT AND EVALUATION, NEW YORK STATE OFFICE FOR THE AGING

Mr. O'CONNELL. I bring regards from Director Callender.

Director Callender cochairs with the commissioner of health in the State, a body known as the long term care policy coordinating council. In this role he has stimulated State bureaucracy thinking on some innovative initiatives in dealing with the area of long-term care.

We don't have all the answers, and in our frustrations with the absence of new direction coming out of the current administration in Washington, we have been looking for State solutions, as opposed to Federal level solutions.

However, in our comments I would like to pretty much follow the questions outlined in the letter of invitation, and talk about the need for home care, the cost effectiveness of services, and the need for innovation in financing of long-term care.

I will speak about some of the home care initiatives under the Older Americans Act, as well as the State aided Communtiy Services for the Elderly Program [CSEP] and touch on DRG's in conclusion.

For this audience, I don't want to get heavily involved in providing numerous statistics. I am sure that you are fully aware of the demographics of aging. But there are a few numbers worth noting. This year the council did projections to determine what the cost of long-term care in New York State would be in the year 2010, if we did not change anything in terms of the manner that we currently provide long-term care with the institutional bias. Of course, there is also a considerable expenditure in the area of home care, where I believe New York State probably consumes about 75 percent of the national home care expenditure, much of this in personal care services here in New York City. The point is that if we don't change anything, our costs are going to increase from the current $3 to $23.3 billion by the year 2010.

Let me begin by describing some of the basic principles that have really guided the decisions that have been made by the State office for the aging, as well as our sister State agencies involved in the council. These principles have not only come from the philosophy of the Older Americans Act, but also from what we have learned from the experiences of providing services to the impaired elderly in the State.

First, is the expectation that the business of government in long-term care is to provide services to those who can not serve themselves. We exist to supplement what is available to private citizens, not to replace those individual and group efforts.

Our task is to see to it that government sets an environment in which people can help themselves and each other, and then assures the provisions of a coordinated set of services to those who are most in need. Further embodied in this principle are the following:

That families should be seen as the nucleus of the long-term care system, to build upon them; that people should not be forced to improverish themselves in order to obtain the needed services—which is what we basically do now under Medicaid, the principal long-term care program in the State; that client management procedures must be developed to help people get the services they need.

It is clear that a more appropriate and equitable form of financing is needed to support long-term care and home care within that. An entirely new approach is needed, one that challenges the Federal and State governments, and the private insurance sector, to participate along with the individuals that are impaired.

Another basic principle is that the nature of the service to be provided to a person needing long-term care should be defined by the unmet needs of that person, not by the particular requirements of a particular funding source, be it Medicare or Medicaid.

What we have now is a long-term care financing system which is driven largely by medical definitions not directly related to the totality of needs of any particular person.

We have defined home care mostly in terms of home health care, home care as being essentially medical in nature. We have been been driven to this mainly because of the way Medicare defines home care.

Let's look in detail at the problem caused by the current system of funding. Medicare definitions of home care are very narrow and oriented toward post acute care in the home, rather than long-term care.

In effect, Medicare defines home care as intensive level home care, and restricts its reimbursement to home care, at this level. Reimburseable in-home services under part A are almost exclusively skilled nursing or medical in nature, provided subject to a care plan devised by a physician and supervised by a registered nurse.

Under part B, home care clients must be totally homebound and needing home care as presecribed by a physician. In 1967, new regulations narrowed reimbursement criteria even more by requiring that recipients must be unable to use their lower extremities.

Home health aides were restriced to bedside care. The 1969 regulations restricted reimburseable services even more by requiring the actual "laying on of hands," in the nursing sense.

Recently, in July of this year, regulations were promulgated to restrict Medicare payments to specialists in skilled nursing care, physical therapy, speech pathology, occupational therapy, by limiting how much these specialists can actually bill Medicare. Payments will be capped a little above the mean charge for these services.

Medicaid does not use the medical approach with the same intensity as Medicare does, but the program remains strongly tied to the definitions derived from acute care. Medicaid does support some nonmedical services, especially in States like New York which have chosen to exercise the option to include a service known as personal care service, known here in the city as the home attendant program.

I would like to add a historical perspective on this. Back in 1972, the predecessor program to the social services title XX—I think title VI at the time—was capped. In other words, once the cap was reached, you could no longer get Federal reimbursement, even if the State continued to expend additional moneys for services defined under title XX.

At the time that the program was capped, New York State was expending in excess of its ceiling over $100 million. Therefore, the State government and the local county social services districts began to shift expenditures from one program to the next to maximize Federal reimbursement. And what we clearly did, and did extensively right here in New York City, was to switch the social service based, non-medical homemaker and housekeeper chore services from the title XX program to title XIX Medicaid funding because Medicaid was open-ended—as it still is today.

Essentially, we took a service that was very effective, though certainly not at the scope that it is today, and we simply put it under medical funding. Therefore, we layered into it additional costs that are entailed in the overall provision of that service, including the physician's prescription, nursing assessment, nursing supervision, and so on.

Medicaid has the additional problem that it was designed as a funding source for medical services for the poor. Medicaid requires that persons become improverished in order to use it.

Medicare supports the provision of skilled medical services, but does not cover those support services which, although not medical in nature, nonetheless have impact on the health of the elderly.

Those services consisting of housekeeper/chore and personal care type services designed to assist persons with functional deficits to carry out the routine activities of daily living in their own homes. In-home support services are health related services, although they are not medically oriented services.

They must be defined broadly to include all services which preserve health and support functional capacity.

Long-term care is not just medical care, as important as medical care is. Long-term care includes a continuum of services of many kinds and intensities.

Home health care is a part of it, but only one part of a coordinated set of services including nonmedical, social and advocacy services that are necessary. Thus, any reform in financing of LTC and home care must include provisions for in-home support services of a nonmedical nature.

With respect to the question of cost effectivenes, certainly home care is attractive for two main reasons.

First is that the elderly themselves tell us in overwhelming numbers that their preference is to remain in their family home environment. They regard institutional long-term care as a resource to be used only when nothing else is available or will work.

The second reason is that our society is facing the appalling costs of institutional-based long-term care, and we seek a less expensive option in home care services.

The claim that home care is less expensive than institutional care remains under attack.

Mr. Biaggi. I was always under the impression that home care was considerably cheaper than institutional care.

Mr. O'Connell. There are those that will say that it isn't. They will say that you have to factor in other cost. For example, someone on Medicaid may also be receiving SSI and you have to add the SSI to the home care payments, food stamps and other benefits programs, and that when you add up the benefit programs that are available they may in fact rival the cost of institutional care. I disagree. When you look at the average institutional care cost which in New York is getting close to $30,000 a year, there is no one who is on SSI that would be accumulating, perhaps with the exception of the rare numbers in New York City's home attendant program that might get 24-hour care, that would approximate that kind of cost in public benefit services. For most, home care is clearly less expensive.

Mr. Biaggi. Excuse me. Who is responsible for those claims, nursing home people?

Mr. O'Connell. No. To be frank with you, I have heard our own New York State Division of the Budget staff raise it.

Mr. Biaggi. We don't pay attention to them.

Mr. O'Connell. Also, I have heard that in many national meetings.

Mr. Biaggi. Thank you.

Mr. O'Connell. New York State recently completed participation in the National Long-Term Care Channeling Demonstration Project, which was carefully designed to study the effectiveness of home care in meeting the needs of the frail elderly and also in containing costs. The great majority of the clients served by the channeling project were so impaired that they met the requirements for placement in a residential health care facility. Nine out of 10 would have, in the absence of the project, likely ended up in a nursing home or hospital.

Despite the severity of their impairment, though, the costs for serving those persons was about 40 percent of the cost of paying for a stay in a nursing home. Institutional placement was prevented or at least delayed for many clients in the program.

The reasons why channeling worked are instructive. Channeling included a fairly standard list of available services of the sort which Medicaid and Medicare will now pay for. In addition, a couple of special aspects of channeling made the greatest difference. First, channeling included a significant case management component, one which included a set of tasks greater than usually done under that kind of a rubric.

We had a careful client assessment process, a well controlled plan of care, monitoring of services delivered and review of cases on an ongoing basis. Channeling paid for a limited number of services not usually paid for under Medicaid or Medicare. This accounted for 15 percent of the budget of the program but nearly a third of the clients needed the services in order to stay at home. Examples were housekeeping, companion services, nonmedical transportation, special home-delivered meals, respite, day care, and so on.

What we learned supports the impressions of many people who work with the elderly in the community. We see that the case management mechanisms are as crucial to success as are some of the direct services that are provided. In addition, some services such as companion and housekeeping, which would not be called medical, make a crucial difference in the total health care of the client.

One problem with current research is that we cannot provide proof that in-home provision of nonmedical services will result in an immediate lowering of public costs. We do not have research to prove that early intervention is a cost-effective instrument. Even the channeling program did not allow us to prove that.

In considering expansion of in-home support service, it is important to view them as preventive services offered at a point before clients become severely incapacitated. The value of prevention has always been difficult to demonstate especially in situations of chronicity. Some gerontologists have suggested that any services designed to keep people in their own homes have benefits which may not necessarily be related to cost savings. Among those are the psychological and emotional benefits for the person who is allowed to remain in family surroundings.

Another is the enhanced sense of self-mastery that comes with the ability to preserve remaining functional capacity, and another is the respite and assistance that the family and informal care givers are given. What price tag can be placed on these kinds of benefits? It is possible that consumers and the State and Federal Governments as partners will have tc expand their funding commitments for in-home support services.

However, the long-range benefits of investing in relatively lower cost in-home support services which builds on the strengths of clients and their informal care givers could be substantial, particularly if those services are delivered based on a thorough assessment of the client and the family's needs and managed in a way which assures that the level of need and the level of service provision are carefully matched.

I think we have to change the context of the cost-effectiveness argument. We must think not only of the cost to the public in tax-supported programs but also of the cost to the individual in need and to those who are the family friends and neighbors of that person. If we do that, I believe that the direction of public policy becomes clear. We must design services and funding to meet the needs of the real persons at risk of more severe impairments, not to meet a budget goal of some arbitrary number of dollars.

I have described how the current methods of financing of long-term care have basically missed the mark because of the over-emphasis on medical services. At the same time, Medicaid, although a significant support, has failed because it is designed as a welfare program and forces people to become more or less impoverished in order to get it. I think another failure of the current financing mechanism is that failure to pool the financial risk adequately. Under the current systems, the first defense against the cost of long-term care are the limited savings and resources of the individual in need. When those are exhausted, Government becomes the payer, or, to be more precise, all citizens suddenly become the payer and share in the cost. We have failed to provide an intermediate pooling of the risk. We burden an unlucky few with the total responsibility until they reach poverty.

The nature of the public debate about long-term care financing must be changed. The solution to the crises we face now is not for Government to consider ways to reduce its financial responsibility for long-term care. The solution is to find ways of spreading the financial burden so that few individuals or a limited sector of society do not bear a disproportionate share. This may require some additional outlays of public funds. We should stop trying to deal with increased needs by merely trying to avoid Government fiscal responsibilities.

Government has other responsibilities to its citizens which need not be so costly. In addition to our responsibilities to those who cannot provide for themselves, Government has the role of setting the context in which a person can make his own choice and own plan to meet his needs. We must set in place new options which make it possible for persons to pool their individual risks of need for long-term care with their own resources. Spreading the financial risks will balance the burden of paying for long-term care.

We need to devise a new means of funding long-term care including in-home services. Call it title 21, Medicare part C, long-term care insurance or whatever, Government must devise a new initiative in cooperation with the private sector and individual citizens to pay for LTC services. Not only must the funding for long-term care be more flexible to pay for a wider variety of services, but it should also allow for more opportunities for persons to plan for themselves. We must allow for options such as privately sponsored long-term care insurance or to pay for insurance through services such as home equity conversion or retirement medical accounts designed along the lines of IRA's and so on.

The State Office for the Aging, through the LTC PCC, is currently involved in examining these options and how they might be implemented both within the resources of the State and complementing Federal initiatives.

With respect to the question of the Older Americans Act and home care, very clearly the established Older Americans Act network in New York State has been very significantly involved in home care. However, we should realize, though, that the financial involvement of the area agencies on aging and the State Office for the Aging is a small part of the whole.

In New York State, for example, the annual long-term care Medicaid budget is now about $3 billion. About $2.5 billion of that actually pays for institutional care while the balance goes primarily into the Personal Care Service Program and other home health care benefits in the State. In contrast, area agencies on aging in New York State spent in 1983 only about $6.2 million. This excluded the Home-Delivered Meals Program.

The difference in expenditure rate is obviously huge, but the difference conceals some important points. For one thing, virtually all the home care services provided by area agencies are contracted out to the same kinds of agencies that are providing Medicare and Medicaid-type home care in the State. Again, although the dollar amounts are small, the impact has been great. The aging network's funds have been spent to help those not eligible for Medicaid or for services not covered by Medicaid or Medicare.

Without the Older Americans Act funds and State community services funds, many elderly would have been forced into impoverishment, spent down to Medicaid eligibility, therefore qualifying them for other benefits or suffered premature institutional care. There also are people without the ability to spend down, whom I believe Ms. Spohn referred to. They are caught in the middle because they don't have the disposable income to be able to buy home care or some other service. This service effort is a reflection of the targeting requirements of the Older Americans Act and the responsibility of area agencies to coordinate their services with other providers to complement the rest of the home care system. Congressional support for expansion of these programs is currently merited.

Mr. BIAGGI. How much more do you have?

Mr. O'CONNELL. Three pages.

Mr. BIAGGI. Summarize, please.

Mr. O'CONNELL. The next area was home-delivered meals, and the question should you expand title 3(c)(2) to include other support services. Our position is that you should not expand title 3(c)(2) to increase the other vital home care services. Rather, you should directly increase title 3(b), the social support services. If Congress is concerned that there perhaps is too broad a use of those services, we would recommend that you consider earmarking some of that increase specifically for the kind of crucial in-home services that we are talking about.

Ms. SPOHN. We second that.

Mr. O'CONNELL. To the point about DRGs, it is only really officially coming to New York State in January, but we have had our own prospective reimbursement system for a number of years. We keep hearing from area agencies that they are being requested by local agencies, primarily certified home health agencies, to contract more with them to pick up some of the costs for people who are being pressured out of the hospitals and acute care settings more rapidly.

We would comment that conceptually we do not question DRG's. Clearly, there has been excessive hospital use. New initiatives are needed. I think we have to examine the implementation of DRG's, learn from the mistakes and make the kind of modifications that are necessary, but not do away with the system.

Thank you.

[The prepared statement of Mr. Eugene S. Callender follows:]

### PREPARED STATEMENT OF DR. EUGENE S. CALLENDER, DIRECTOR, NEW YORK STATE OFFICE FOR THE AGING

Honorable Chairman and members of the Subcommittee, I am pleased to join with you this morning on behalf of the New York State Office for the Aging as we look at ways to improve home health care for the elderly.

We have made substantial progress during the past few years in understanding what frail older persons need in order to live decent lives and how we can see to it that those needs are met. Despite our efforts, much remains to be done. I appreciate this opportunity to describe what York State has learned in providing home care services for the elderly and what we see as the next steps.

I will speak today about issues related to the need for home care, the cost-effectiveness of services and the need for innovations in financing long term care, including home care. I will speak about current home care initiatives taken by the Older Americans Act-funded aging network, including the major role of home delivered. Finally, I will put this in the light of what the new DRG mechanism may ask of us in the aging network.

I will not repeat the demographic and cost-impact figures about which we are all familiar. However, one recent cost projection merits your attention. Work under the Long Term Care Policy Coordinating Council has recently noted that if there is no change in the way we manage LTC in New York State, by the year 2010 LTC cost will skyrocket from the current $6 billion to $23 billion.

Let me begin by describing the basic principles which guide the decisions made by the New York State Office for the Aging and for that fact those of DDS, DoH and other agencies involved in LTC. These principles have come not only from the philosophy of the Older Americans Act, but also from what we have learned from the experiences of providing services to impaired elderly in New York State. First is the expectation that the business of government in long term care is to assure services for those who cannot serve themselves. We exist to supplement what is available to private citizens, not to replace those individual and group efforts. Our task is to see to it that government sets an environment in which people can help themselves and each other, and then assures the provision of a coordinated set of services to those whose needs are not being met.

Further embodied in this principle are the folowing:

That families should be seen as the nucleus of the LTC system;

That people should not be forced to impoverish themselves in order to obtain needed services; and

That client management procedures must be developed to help people get the services they need.

In addition, it is clear that a more appropriate and equitable form of financing is needed to support LTC, home care. An entirely new approach is needed, one that challenges the Federal and state governments and the private insurance sector to participate along with individuals.

Another basic principle is that the nature of the services to be provided to a person needing long term care should be defined by the unmet needs of that person, not by the requirements of a particular funding source. What we have now is a long term care financing system which is driven largely by medical definitions, not directly related to the totality of needs any particular person may have.

We have defined home care mostly in terms of home health care, i.e., home care as being essentially medical. We have been driven to this mainly because of the way Medicare defines home care. Let us look in detail at the problems caused by the current system of funding.

Medicare definitions of home care are very narrow and oriented towards post-acute care in the home, rather than long term care. In effect, Medicare defines home care as intensive level home care and restricts its reimbursement to home care at this level. Reimbursable in-home services under Part A are almost exclusively skilled nursing or medical in nature, provided subject to a care plan devised by a physician and supervised by a Registered Nurse, a Licensed Practical Nurse, or a Licensed Vocational Nurse.

Under Part B, home care clients must be totally housebound and needing home care as prescribed by a physician. Other regulations narrowed reimbursement criteria even more by requiring that recipients also be unable to use their lower extremities. Home health aides were restricted to bedside care. The 1969 regulations restricted reimbursable services even more tightly by requiring the actual "laying on of hands" in the nursing sense. Very recent (July, 1985) regulations were promulgated to restrict Medicare payments to specialists in skilled nursing care, physical therapy, speech pathology and occupational therapy by limiting how much these specialists can bill Medicare. Payments will be capped a little above the mean charge for these services.

Mediciad does not use the medical approach with the same intensity as Medicare does, but the program remains strongly tied to the definitions derived from acute care. Medicaid does support some non-medicial services, especially in states like New York which have chosen to exercise the option to include such services as personal care. Those non-medical support services, however, can only be included as the result of plan devised by a physician and put into operation under the supervision of nurse and other professionals. The bias towards acute care and medical services is clear.

(It should be noted that prior to the capping of the Social Security Act Title XX Support Services program in 1972, what are now known as Personal Care Services under Title XIX, were actually funded under Title XX as homemaker and housekeeper/chore services without the overlay of physicians orders and nursing assessment and supervision.)

Medicaid has the additional problem that it was designed as a funding source for medical services for the poor. Medicaid requires that persons become impoverished in order to use it. Medicare supports the provision of skilled medical services, but does not cover those support services which, although not medicial in nature, nonetheless have an impact on the health of the elderly.

Those services are non-medical supportive services consisting of housekeeping/chore and personal care assistance. They are designed to assist persons with functional deficits to carry out the routine activities of daily living in their own homes.

In home support services are health-related services, although they are not medically-oriented services. They must be defined broadly to include all services which preserve health and support financial capacity.

Long term care is not just medical care, as important as medical care is. Long term care includes a continuum of services of many kinds and intensities. Home health care is a part, but it is only one part of a coordinated set of services including non-medical social, nutritional and advocacy services. Thus, any reform in the financing of LTC and home care must include provisions for in-home support services of a non-medical nature.

### (A) COST EFFECTIVENESS

Home care is attractive for two main reasons. First, the elderly tell us in overwhelming numbers that their preference is to remain in their familiar home environment. They rightly regard institutional long term care as a resource which is to be used only when nothing else will work. The second reason is that our society is facing the appalling costs of institutional based long term care, and we seek a less expensive option in home care services.

The claim that home care is less expensive than institutional care remains under attack. For some, it is clearly less expensive to remain at home. New York State recenty completed participation in the National Long Term Care Channeling Demonstration Project which was carefully designed to study the effectiveness of home care in meeting the needs of frail elderly persons and in containing costs.

The great majority of the clients served by the Channeling Project were so impaired that they met the requirements for placement in a Residential Health Care Facility. Nine out of ten would have, in the absence of the project, likely ended up in a nursing home or hospital.

Despite the severity of their impairments, though, the costs for serving those persons was about forty percent the cost of paying for a stay in a nursing home. Institutional placement was clearly prevented or at least delayed for many of the clients of the program.

The reasons why the Channeling Demonstration Project worked are instructive. Channeling included a fairly standard list of available services, of the sort which Medicaid and Medicare will now pay for. In addition, a couple of the special aspects of Channeling made the greatest difference. First, Channeling included a significant case management component, one which included a set of tasks greater than is usual. We had a very careful client assessment process, a well-controlled plan of care and monitoring of services delivered, and reviewed case progress regularly.

In addition, Channeling paid for a limited number of services which are not usually paid for under Medicare or Medicaid. This kind of service accounted for only fifteen percent of the budget of the program, but nearly a third of the clients needed these services in order to stay at home. Examples include housekeeping, companion, non-medical transportation, special home delivered meals, chore, day care and respite care.

What we learned from the Channeling Demonstration supports the impressions of many people who work with the elderly in the community, i.e., that case management mechanisms are as crucial to success as are the direct services provided. In addition, some services such as companion and housekeeping which would not be called "medical" make a crucial difference in the total health of the client.

One problem with current research is that we cannot provide proof that in-home provision of non-medical services will result in an immediate lowering of public costs. We do not have research to prove that early intervention is a cost-effective investment. Even the Channeling Demonstration did not allow us to prove that.

In considering expansion of in-home support services, it is important to view them as preventive services offered at a point before clients become severely incapacitated. The value of prevention has always been difficult to demonstrate, particularly in situations of chronicity. Some gerontologits have suggested that any services designed to keep people in their own homes have benefits which may not necessarily be related to cost savings.

Among those are the psychological and emotional benefits for the person who is allowed to remain in familiar surroundings. Another is the enhanced sense of self-mastery that comes with the ability to preserve remaining functional capacity, and yet another is respite and assistance to informal caregivers.

What price tag can be placed on these benefits? It is probable that consumers and the State and Federal governments as partners will have to expand their funding commitments for in-home support services. However, the long-range benefits of investing in relatively lower cost in-home support services which build on the strengths of clients and their informal caregivers could be substantial. This benefit could be substantial particularly if those services are delivered based on a thorough assessment of client and family needs and managed in a way which assures that level of need and level of service provision are carefully matched.

I think we have to change the context of the cost-effectiveness argument. We must think not only of the cost to the public in tax-supported programs, but also of the cost to the individual in need and to those who are the family, friends and neighbors of the one in need. If we do that, I believe that the direction of public policy becomes clear. We must design services and funding to meet the needs of the real persons at risk of more severe impairments, not to meet a budget goal of some arbitrary number of dollars.

We will have to find new ways of financing long term care. If we are serious about fulfilling government's responsibility to meet the needs of those who cannot serve themselves, I do not see that we have any choice but to undertake such new initiatives.

### (B) NEW METHODS OF FINANCING LONG-TERM CARE

I have described how the current methods of financing long term care miss the mark because of the over-emphasis on medical service. At the same time, while Medicaid has been the significant fiscal support for LTC services, it is a failure in forcing individuals to impoverish themselves before obtaining support.

Observe what happens now. Long term care is required for persons who, usually after years of independence and self-support, find themselves incapable of meeting their own basic needs for survival. To continue to live, they must supplement with purchased services what their families, friends and neighbors can provide.

When the individual elderly person can no longer pay for his or her own care by having spent down into poverty, Medicaid then becomes the payor. The financial burden his then shifted from the individual in need to the government. The most severe stress is put on local and state governments with their limited abilities to tax to pay the costs of needed care.

The failure of the current financing system, is the failure to pool the financial risk adequately. Under the current system, the first defense against the costs of long term care are the limited savings and resources of the individual on need. When those are exhausted, government becomes the payor, or, to be more precise, all citizens suddenly share in the cost. We have failed to provide any intermediate pooling of the risks. Instead of all persons sharing smaller parts of the risk, we burden an unlucky few with the total responsibility until they reach poverty.

The nature of the public debate about long term care financing must be changed. The solution to the crisis we face now is not for government to consider ways to reduce its financial responsibility for long term care. The solution is to find ways of spreading the financial burden so that a few individuals or specific sectors of society do not bear disproportionate shares. This may require some additional outlays of public funds. We should stop trying to deal with increased needs by merely trying to avoid government fiscal responsibility. Government has other responsibilities to its citizens, though, which need not be so costly.

In addition to its responsibilities to those who cannot provide for themselves, government has the role of setting the context in which persons can make their own choices to plan for their own needs. We must set in place new options which make it possible for persons to pool their individual risks of need for long term care with their own resources. Spreading the financial risks will balance the burden of paying for long term care.

What we need is a new means of funding long term care, including inhome services. Call it a Title XXI to the Social Security Act, Medicare part C, Long Term Care Insurance, or whatever, government must devise a new initiative in cooperation with the private sector and individual citizens to pay for the service needs of an increasing number of persons unable to care for themselves.

Any new funding mechanism must be more flexible than any now in place. We need to fund long term care in ways which make it possible for people to plan for their own long term care needs to the extent possible, and for government to be able to help those with limited finances to pay for care without the threat of impoverishment. The conceptual underpinning for such an initiative is that the basic determining factor should be the needs of the person, not a definition of a service as being medical or social.

Not only must the funding for long term care be more flexible to pay for a wider variety of services, but it should also allow more opportunities for persons to plan for themselves. We must allow options, such as privately-sponsored long term care insurance, or, to pay for insurance or services through home equity conversions or "individual retirement medical accounts" designed along the lines of present I.R.A.s. The New York State Office for the Aging is currently involved in discussing such options with other Departments and Agencies of State Government. We would welcome, and indeed urge, the support of this Subcommittee in elevating our state-level discussions to a national arena.

### (C) THE OLDER AMERICANS ACT AND HOME HEALTH CARE

The Older American Act established a network of services for the elderly, with a particular focus on the provision of community-based long term care services in the homes of the elderly. We should realize, though, that the financial involvement of the area agencies on aging is a very small part of the whole. In New York State, for example, the annual LTC Medicaid budget is about $3 billion, of which $2.5 billion is spent for care of persons in institutions.

In contrast, in 1983, Area Agencies on Aging in New York State spent, only about $6.15 million (excluding home delivered meals) from the Older Americans Act and state aid funds on home care services. The difference in expenditure rule is obviously huge, but the difference conceals important points. For one thing, in New York State virtually all of the home care services provided by Area Agencies on Aging are provided under contract to other agencies—usually non-profit or public agencies. These are the same agencies which are providing services reimbursed under Medicare and Medicaid. Area Agencies on Aging are thus already deeply involved in home care, although their budget amounts are comparatively tiny.

Again, although the dollar amounts are small, the impact has been great. The Aging network's funds have been spent to help those who are not eligible for Medicaid, or for services not covered by Medicaid or Medicare. Without Older Americans Act funds, many of those clients would have been forced into impoverishment (and Medicaid eligibility through spenddown) or premature institutional care. This service effort is a reflection of the targeting requirements of the Older Americans Act, and the responsibility of Area Agencies on Aging to coordinate their services with other providers to complement the rest of the home care system. Congressional support for expansion of these home care initiatives of the aging network is certainly merited.

### (D) HOME DELIVERED MEALS

The committee asked for comments on recommendations on expansion of home delivered meals funding to provide additional supportive services. First let me summarize some of what we have learned in New York State from home delivery of meals.

Provision of nutritious meals is obviously valuable in itself. We have found, as was expected, that providing meals has also served as a useful tool for identifying persons at risk of other harm, especially when meals are delivered to a person at home. One result of our experience with persons at home through the Title III-C-2 home delivered meals program was the discovery of many persons at substantial risk.

In the past year, New York State began a Supplemental Nutrition Assistance Program (SNAP) using state aid funds. These SNAP projects include intensive outreach to find persons who have not been served by existing III-C programs, or whose needs cannot be met by such existing III-C programs, or whose needs cannot be met by such programs. The SNAP projects are designed to provide food and nutrition education, and to link persons at risk with other services.

What we have learned from this is that nutrition services must be linked with other social and support services. We would support very strongly any proposal to increase III-C-2 funding to provide more meals. We believe, however, that it is conceptually unsound to use III-C-2 funds to increase the allocation of in-home support services that could be funded under III-B. The concept of coordinating social and health services for those receiving home delivered meals makes a better design, we believe. Since III-B funds can be broadly utilized if Congress desires to increase home care funding solely, it could earmark increases for such services.

It is clear that substantial unmet need still exists in New York State, and would urge this Subcommittee to regard favorably any proposals to improve funding levels for both nutrition and social services.

### (E) THE IMPACT OF DRG'S

New York State anticipates further pressures to provide in-home services when Medicare's prospective payment mechanism of diagnosis related groups (DRGs) is introduced in New York State. What we can expect to see, though, was clearly described in a survey taken by the Southwestern Gerontological Center among Area Agencies on Aging in areas where DRG reimbursement is already in place. Older persons there were discharged from hospital "sicker and quicker" as had been predicted. The Area Agencies reported that they faced increased demands for home delivered meals, home care services, and case management. Clearly, implementation of DRGs provides additional arguments for Congress to significantly increase in-home support services funding provided under Titles III-B and III-C-2, as well as the Social Security Act titles.

I should note that quicker discharge from hospitals due to the DRG system need not necessarily be thought of as a bad thing. It is clear that a pattern of excessive use of hospitalization for the elderly has developed because of the ease with which Medicare paid for such care. It is appropriate that we change that, and the New York State Office for the Aging has long supported policies which reduce dependence on any form of institutional care. As with any new initiative, we can expect experience will teach us that some changes will need to be made in the original design, but I wish to underline our support for actions which reduce institutionalization. Our concern is that there be in place an effective network of in-home support services to help those elderly returning from shorter hospital stays.

### (F) CONCLUSION

In conclusion, I think that we can learn from our past successes and difficulties. We have found that home care services can be beneficial to many elderly, sometimes, demonstrably preventing or delaying institutionalization and consequently saving money. A crucial factor is the presence of strong case management functions to assess need and to link the various providers of services to the individual older person.

I commend the Congress for the initiative it has shown in supporting the development of an aging network in this country. The network has provided services which have, for many elderly, filled the gaps left by other service and funding systems. The New York State Office for the Aging looks forward to continuing to work with this Subcommittee and the Congress to use what we have learned to make the lives of frail elderly more fulfilling. Thank you.

Mr. BIAGGI. Thank you. I have a number of questions and so does my colleague, Mr. Manton, but in the interest of time and to indulge some of our witnesses, we will send the questions to you and, hopefully, you will respond to us for the record. Your entire statement will be included in the record, Mr. O'Connell.

Mr. O'CONNELL. I would like to comment on the question of the SSI and the one-third reduction. In New York State it would cost the State government $75 million to do away with the one-third reduction right now. Clearly, some of the people who would get that money could use it to enhance their ability to remain at home, but I am not sure that everybody would.

Frankly, I think we have to look at, if we are going to have the availability of a new pool of funds based on changing that concept, that we have to target that $75 million to people who definitely need it for the purpose of remaining at home as opposed to just spreading it to everybody.

Mr. BIAGGI. I see. In a sense it is a needs test, right?

Mr. O'CONNELL. That part of it would be, yes, a service needs test.

Mr. BIAGGI. Thank you very much.

The next witnesses are Mary Lou Carraher, Visiting Nurse Association of New York, and Charles Trent, executive director, East Harlem Committee on Aging, who has with him Ethel Husney, Constance Swinton, and Domingo Mendez, care provided through Project LIFE. Mr. Trent, is Joan Marren here? She is director of home care at Mount Sinai.

## STATEMENT OF MARY LOU CARRAHER, VISITING NURSE ASSOCIATION OF NEW YORK

Ms. CARRAHER. Thank you for the opportunity to present this testimony today. Ms. Griffith was unable to attend the entire meeting so I will appear in her stead. The first thing I would like to address is something you discussed with Dr. Butler, the training component in the home health care field.

There are numerous levels of people who are currently assisting in the home, the home attendant, the personal care worker, the home health aid, homemakers. In New York State, the home health aide is required to participate in a mandatory training program and also have ongoing inservice education. In many other States this is also true. There is a curriculum published by the National Home Caring Council in New York that outlines the basic training.

In New York State, in addition, a home health aide must, before completing that training, have 10 supervisory visits by a registered nurse before she actually receives her certificate saying that she is in fact trained. So I think these people coming over the threshold of unemployment, which is true, are not going in untrained to provide home health assistance.

For the past 92 years the Visiting Nurse Service of New York has provided quality home care to people of all ages and levels of income. Some of you may be familiar with Lillian Wald, the founder. Her commitment was to provide dedicated compassionate service to patients at home. We have continued this commitment for many years.

In 1984 the Visiting Nurse Service was reorganized, and VNS home care was organized as a service arm of the agency. It uses a delivery model comprised of five specialized areas of care, acute care, maternal child health/pediatrics, preventive care, care of the terminally ill, and long-term care.

The long-term care program currently has two components. The long-term home health care program [LTHHC] also known as the Lombardi Nursing Home Without Walls program, and the geriatric long-trm care.

In addition, VNS home care provides nursing assessment to agencies who provide home attendants, homemakers, and housekeepers through the Department of Social Services program.

In 1984, VNS home care made 1,250,000 visits to almost 75,000 patients in the boroughs of Manhattan, Queens, and the Bronx. Sixty-four percent of these people were over the age of 65, and 15 percent were 85 or older.

Visit frequency and length of time a patient is seen varies. Our nurses, working closely with the physician, the social worker, the patient, and the family, develop the plan of care.

Depending on their needs, some patients are seen daily and some only once a month. Some receive care for a short period of time while others are cared for over a long interval. The patients we serve in the long-term home health care program are most often seen over a long period of time.

Congressman Biaggi, in your letter requesting our participation in this hearing, you asked us to address certain questions and certain issues related to home health care and the elderly.

The first question was how valid is the assessment that home health care services for the most part are more cost-effective than nursing home care.

In State after State, the data are coming in. In New York, the long-term health care program has been operating since 1978 and has shown that the cost of services for patients in the program approximates 50 percent of the costs of corresponding institutional care. This program is available to eligible Medicaid patients who would otherwise have been institutionalized.

In our agency, we are seeing over 400 patients in this program. We use a coordinated case management approach and on a long-term basis with care directed by a primary care nurse.

The services these patients receive include nursing, home health aide service, personal care service, medical social services, dietary consultation, rehabilitation, laboratory services, medical supplies and equipment or those things that they would receive in a nursing home if they had been institutionalized.

In addition, the program provides waivered services, such as social transportation, day care, and respite care.

The New York program has a fiscal cap set at 75 percent of the cost of caring for patients in a skilled nursing facility or health-related facility.

Roughly, in VNS home care, we are averaging 67 percent of the cost of caring for patients in a skilled nursing facility in our long-term home health care program.

We are slightly higher than the State average, but we believe that in the city we care for patients with more complicated medical and social problems than we see in other parts of the State.

We make every effort to use a patient support network including family and significant others.

In Illinois, to go to another State, the Five Hospitals Homebound Elderly Program found that over a 4-year period, the mean cost per patient in this program was $2,277.33—1980 dollars—compared to $11,000 to $13,000 a year being charged for comparable care in a Chicago area nursing home.

Reporting in 1983 in Caring magazine, Dr. Susan Hughes of Northwestern University tracked a sample of 122 of these patients and 123 controlled patients and found 13 percent of the Five Hospitals Homebound Elderly Program patients were admitted to institutions versus 23 percent of the control group.

No increase in the use of hospital services in either group despite the fact that the five hospitals group was older and medically underserved at the onset of the study.

No difference in mortality rates despite the fact that the five hospital group was an average of 3 years older and more impaired at the onset—a slight increase in the perception of social, mental, and physical well-being of the five hospitals groups versus the control group.

In Georgia, the Georgia alternative health services project offered alternative services for an experimental group of persons who would have otherwise been placed in a nursing home.

In addition to regularly financed Medicaid services, adult day care rehabilitation services, home-delivered meals and alternative living arrangements were offered. A control group was used.

The preliminary findings reported that Medicaid nursing home costs for the control group were on the average 33 percent higher than for the experimental group.

Physicians' costs reimbursed by Medicaid are 141 percent higher for the control group, and mean Medicaid in-patient hospital costs are 49 percent higher for the control groups.

In July 9, 1985, testimony before the U.S. House Select Committee on Aging, Florida Gov. Robert Graham reported that in 1984, the average Medicaid nursing home cost was $12,000 per patient, compared to a $3,400 per patient cost under the State Medicaid 2176 Waiver Program.

In Arkansas, a program for in-home services for the frail elderly in eminent danger of institutionalization, produced substantial savings in public outlay.

For the extremely impaired, costs at home were comparable to costs for patients in nursing homes, but only 30 percent of the costs were paid with public funds, whereas almost all facility costs were paid for from public funds.

The largest portion of care at home for patients at all levels of impairment were provided by family and significant others.

The last study points out that for some patients the cost of caring for the patient at home can be as costly as nursing home care.

This leads us to address your next question: Is home care more applicable for certain segments of the elderly population?

We do not believe that home care is a panacea for all the elderly who require care. We believe the patient care needs have to be addressed on an individual basis. Patients can't be easily segmented and categorized.

A care option that works for an 80-year-old patient who has recently had a stroke may be entirely wrong for another 80-year-old patient with the same deficits following a stroke.

Only through careful assessment by a primary care community nurse of the patient's health, his mobility, his living arrangements, the family support, his express desires, can the right decision for care be made.

Generally, we believe it is misleading to use the nursing home bed cost as a basis for determining the cost of caring for a needy elderly person. All providers of care for the elderly need to work together to develop a new system of care with a variety of options.

We then need to refine the system to make it cost-effective and change the reimbursement structure for that service.

Then we will no longer use the nursing home bed cost as the basis for determining the cost of caring for an elderly person.

Your next question related to the impact that the DRG prospective payment system has had on home care. Since the acute care facilities in New York State have not yet been affected by this payment system, we don't have a lot of firsthand experience to report, but recently we have been admitting patients who are in need of more care, especially what is referred to as high-technology care.

We have responded by implementing a 24-hour, 7-day-a-week care and a high-technology nursing capability.

In addition, we are receiving patients who have stayed in an acute care facility for less time than they may have just a few years ago.

In other words, a so-called sicker and quicker phenomena has begun in New York.

We are aware of two recently released studies, one national and one from Washington State, that found that the DRG system has a significant effect on the extent and range of services being provided by home health agencies.

Next year at this time, perhaps we can answer this question in more depth for you.

The next question relates to the Medicaid waivers under section 2176 of the Omnibus Reconcilliation Act. We believe the waivers should be extended.

The current limited Medicare and Medicaid home health agencies benefits do not provide adequate coverage of services necessary to foster independence while receiving appropriate care at home and do not extend services to all relevant programs.

Consider Emma S., one of our long-term home health care patients. Emma lives in Queens. She is 80 years old. She lives with and cares for her husband who has Alzheimer's disease. He has rapidly deteriorated in recent years.

Emma is a diabetic and is almost totally blind. She is obese, weighing over 300 pounds and has difficulty getting around.

Last year, she needed urinary tract surgery, which left her with permanent tubes extending from both of her kidneys. The dressings around the tubes need to be changed twice a week.

The couple's daughter lives nearby and visits her parents nightly. A VNS home care nurse visits Emma twice a week to change her dressing and to counsel her in planning nutritional meals and to generally assess Emma and her husband.

A home attendant comes every day to assist Emma with the tasks that she is unable to do for herself.

Emma and her husband have an emergency alert response system, so when they are all alone, Emma can summon help immediately if needed. This decreases her feelings of isolation and reduces her need for supervision, while still allowing her to maintain the little independence that she has.

Emma is comfortable in her own place. Her surroundings are familiar to her. With a little help, she finds her way around her home. Without the array of services provided to this couple through the long-term home health care program, both Emma and her husband would need to be institutionalized.

The last question regards copayments. In a recent letter to you we strongly opposed copayments and were pleased to hear the President's 1986 budget proposal to impose the $4.80 copayment on home health on Medicare beneficiaries was dropped.

We believe home health copayments would have the effect of discouraging many elderly persons from continuing needed care because they might not be able to afford the copayment.

We know from experience that providing cost-effective home health care when it is needed often prevents or eliminates hospitalization or rehospitalization, which increases Medicare costs.

Besides the potential impact on the patient, any copayments would require us to incur increased administrative costs. It requires the production of two separate bills, the maintenance of two accounts receivable, additional first class mailing, and additional collection expenses.

We think there are better ways to contain Medicare expenditures.

Congressman Biaggi, thank you for the opportunity to meet with you and present this testimony.

Mr. BIAGGI. Thank you.

Dr. Trent.

## STATEMENT OF DR. CHARLES TRENT, EXECUTIVE DIRECTOR, EAST HARLEM COMMITTEE ON AGING, NEW YORK CITY, ACCOMPANIED BY BETSY TUFT, ASSISTANT DIRECTOR, PROJECT LIFE HOME CARE; AND ETHEL HUSNEY, CONSTANCE SWINTON, AND DOMINGO MENDEZ, CLIENTS, PROJECT LIFE

Dr. TRENT. I am pleased to be here to speak for Project LIFE, a social model of in-home programs funded by the New York City Department for the Aging.

I have a statement I would like to mail to you if I could.

Mr. BIAGGI. That would be included in the record.

Dr. TRENT. I will speak extemporaneously now.

I have heard an awful lot today in terms of policy about in-home care. For the last 7 years my experience in home care has been quite rewarding. A lot of the reward has been based on our efforts to help older people begin to make their environments habitable and I think, that when we view seniors as isolated, as victims, as impoverished, and create systems to do those types of things, we dehumanize them in ways that we are not really able to fully evaluate.

When we do evaluate seniors through assessments and followups, and so forth, what are we doing? Are we creating jobs for professional people, or are we establishing some criteria through which we develop better models of in-home treatment? The in-home treatment that we provide seems to be a preventive system that is not counted into the cost.

For example, when our staff remove wires that might trip seniors and cause falls that would require hospitalization; how much does that cost?

When our staff remove refuse from homes that could cause fires that burn down entire buildings; how much does that cost?

When we get into these debates about cost-effectiveness, and so forth, relative to in-home care, we are talking about a lot of things that we haven't factored in yet, so that I wouldn't be able to tell you very much more about cost effectivness as it applies to in-home care from title 3(b), because that is not our main concern.

We are mostly concerned about taking a supervised social worker point of view into homes to look at a range of unmet needs and factoring that range of unmet needs into a treatment or care plan that we hope is a holistic way of dealing with seniors. If they have medical needs we take them, escort them, to hospitals.

We follow them through these hospitals and we bring them back home. If they are hospitalized for chronic or acute conditions for a month or so, we hold their apartments until the seniors return home.

In that way these persons do not end up on the street. Because one of the things that happens in too many cases is that homelessness is an unintended consequence of our institutional programs. How does that happen?

We have a case of an 84-year-old man living in public housing, paying $101 rent. He had an income of about $350. The institution decided that care would be better provided by a nursing home which was located in a distant county. The man lost his home. If the nursing home system fails, there is no safety net to prevent that man from being on the street.

Meanwhile he has given up his home, security and community interactions. The community has also lost because it loses a per capita cost every time someone is transferred out of its boundaries. One of our major goals is not to transfer people out into institutions.

It doesn't make sense because then we would be destabilizing the community, and at the same time decreasing the aged population in the community.

Rather than my going on and on into those areas, I would rather submit something for the record and let the people who have been here with me for a long time speak for themselves.

If you have any questions I would be glad to answer them.

[The prepared statement of Dr. Trent follows:]

## PREPARED STATEMENT OF DR. CHARLES H. TRENT, EXECUTIVE DIRECTOR, E.H. COMMITTEE ON AGING, INC., AND DIRECTOR, PROJECT LIFE HOMECARE, NEW YORK, NY

Mr. Chairman, we are pleased to be invited here today to testify on the topic, *Home Health Care—Its Present and Future.* As Director of a Title IIIB-funded home care program, my intention is to present the effects of this program on the elderly who live in East Harlem, New York. For the sake of continuity, the program—Project LIFE—is described more fully in Attachment "A" at the end of this report and a brief description of East Harlem's elderly population is found in Attachment "B".

Accompanying me today, Mr. Chairman, are three seniors who as users of Project LIFE's services have their testimony to give. Please let me introduce Mrs. Swinton, Mrs Husney and Mr. Mendez. These three nice people were escoraged here today by some of our key staff: Betsy Tuft, Assistant Director; Lisa Morancie and Gueisy Aponte, Social Workers who work with the seniors in their homes.

Mr. Chairman, you have suggested that I take into account these factors in my testimony: 1) cost-effectiveness of home care vs. that of institutional care; 2) whether or not home care affects the independence and dignity of seniors; 3) the nature and scope of federal barriers that inhibit delivery of home care; and 4) needed federal improvements. Let us talk about the issue of cost-effectiveness first.

### COST-EFFECTIVENESS OF HOME CARE VERSUS THAT OF INSTITUTIONAL CARE

Mr. Chairman, as funds become increasingly scarce and the needs for alternatives to institutional care become more apparent as means to meet the unmet needs of a growing elderly population, the question of cost-effectiveness has been deemed to be vital on the social service and political agenda. We on the direct service lines find this to be very ironic because it is well-known that since the mid-1960s health care and nursing home institutions have spent billions of dollars of our tax money, especially Medicare and Medicaid funds. There is a consistent and long debate as to whether or not this very long, high cost expenditure on institutions has been of observable value to great numbers of our elderly, especially minority elderly and others who live in communities similar to this one. And yet, over the course of these years, this institutional bias has assured that home care services and programs would not grow and develop in line with the defined unmet needs of an increasingly frail sector of our elderly population and in view of significant numbers of chronically ill elderly who had no access either to institutional treatment or to home care at the community level of care. Nevertheless, now the question of cost-effectiveness is being raised after billions of dollars have been squandered on institutional care over the past 20 years or so.

On the other hand, when we take a close look at programs that use the social service model such as the Project LIFE design, the cost-effectiveness of some home care can be categorized by type of potential savings (this is especially relevant since very little is known about the aggregate costs invested in either home care or in institutional care). Cost effectiveness to us means to what extent does Project LIFE meet the stated objectives of the Older Americans Act. One of the most outstanding objectives expressed in this legislation is to prevent institutionalization of seniors. During the past year, more than 250 seniors have been treated by our home care staff (social workers and paraprofessionals) and only 1.2% of these seniors were permanently institutionalized (see an interesting case in Attachment "C"), although a few more seniors were hospitalized for brief periods and returned home.

A main difference between the seniors who were hospitalized while being followed by Project LIFE's staff and the seniors who were hospitalized on their own and not followed formally is that the former were discharged home after a brief stay while the latter were more likely to be held in the hospital in an at-risk status because of a lack of available home care. Being held at-risk and hospitalized held true in many instances when the unattached senior had no illness or disease rationale for continued treatment in a hospital. Therefore, home care is important as a means to make it more likely that seniors who are hospitalized for brief treatment can be returned home once the rationale for hospitalization has been removed.

Home care can be very effective at keeping chronically-ill seniors in their residences, even while recuperating from surgery and other kinds of serious treatment. Home care is also important in very concrete ways as a cost-savings mechanism in the communities. Removal of accumulated boxes and waste from seniors' homes as we do prevents costly and destructive spontaneously-combusted fires that take seniors lives and destroy valuable housing. We in home care evalute the environment for threats to seniors' health and safety and we participate and take leadership in implementing kinds of controls that help to prevent serious household accidents (falls, burns, etc.) that might require institutional intervention and, thus, increased insurance and health care costs. We help to prevent increased investment in costs for police protection and property insurance by evaluting the security of seniors' environments, providing information that takes into account their fears and anxieties related to their personal safety and by securing devices that increase the security structure of environments. We help to prevent colds, flus, pneumonia and bronchial problems in winter by making certain that the seniors' environments are heated under the control of property owners and we monitor seniors in extremely hot weather for illnesses related to the heat. Our regular home care monitoring frequently prevents expenditure of more taxpayer dollars and often remediates some of the burdensome problems that may plague our deservedly needy seniors: low or marginal incomes, decreasing savings, inadequate nutrition, all of which can interact to cause deterioration in some seniors' physical and mental health and emotional stability. The provision of home care helps to define the impact of social and environmental factors on the health of seniors and, thus, has a positive influence on the independence and dignity of the seniors to whom we provide treatment and care.

### EFFECTS OF HOME CARE ON INDEPENDENCE AND DIGNITY OF SENIORS UNDER PROJECT LIFE'S CARE

We view seniors who use Project LIFE to have independence when they can be observed to be able to make adequate decisions to control their environments and their social functioning: interactions with family members where feasible, control of life styles and livelihoods within the framework of their particular cultures, values and norms. Therefore, we use home care as a support to the objectives and goals of the senior individual or family within the framework of their authority and power and not as an intervention that creates a state of dependency, passivity and hopelessness on the part of seniors. This does not mean that a senior who returns home from hospital discharge has no dependency needs or that a senior who has lost physical stength in an extremity is not newly dependent on others for awhile. Our service objective is to evaluate the senior for both strengths and nonstrengths and to stabilize the senior's abilities in parameters agreed upon by the family where one exists to help the senior to develop or to maintain the capacity to use strengths independently and to increase the capacity of the senior to use non-strengths more independently over time. For example, we in home care evaluate abilities of seniors to maintain their environments and provide supportive short- or long term maintenance of only those areas within the environment where nonstrengths of the seniors are apparent. In addition, we allocate limited time for such assistance, which helps to motivate both our staff and the seniors to set the most important priorities for treatment and to work together in planning and in treatment activities so that time is used appropriately.

We monitor, assesses and reassess in the homes on a planned schedule and find that most of the seniors with whom we work report feelings of pride and they can be observed to act with dignity and pride and to have self-esteem. We do not tamper with their identity, or treat them as if they were a number, or critize and prejudge them; we do not use agism, racism or sexism as reasons to remove seniors from their homes and ship them to distant and unfamiliar surroundings. But we do find each senior to have unique unmet needs combined with a host of untapped skills and abilities that have accrued over their long lives, all of which are channeled toward their adequate coping and growth in their own residences. Interestingly, most of our work in home care is accomplished within the construct of many federal and local barriers to treatment of seniors.

### HOME CARE AND INHIBITING FEDERAL BARRIERS

Probably the greatest inhibitions to home care intervention are the federal policies that are biased toward institutionalization of senior and utilization of medical authorities over treatment choices. This bias helps to cause senior citizens to become dependent and poverty-ridden and yet poorly treated. Some of the main consequences of this bias are (1) Diseased parts of senior citizens may be treated if insurance programs pay but such parts are not treated if not covered by insurance; (2) Seniors must usually give up their sense of control at home and render themselves under the control of strangers in institutions; (3) Personnel in such institutions usually do not know about or have interest in possible causal factors within the environment, the senior's culture, family orientation, social values and background and prior history of mental health as tools to be considered in the treatment planning; and (4) Local communities are prevented from developing adequate community-based systems for treatment and social mainstreaming of potentially able seniors.

Finally, there is also a bias toward short term treatment of acute problems, while many seniors have unmet needs for long term treatment of chronic problems.

### RECOMMENDATIONS FOR IMPROVEMENT AT THE FEDERAL LEVEL

In addition to an adequate funding base for home care, there is great need for an overall home care policy that gives direction to the American families and individuals with respect to needy senior members. Such a policy would be constructed around an equitable distribution of home care so that needy seniors have a better chance of being accepted into home care programming.

At the present time home care policies emanate from various and diverse kinds of legislation (Title XX, Title XIX, Title XVIII, the Older Americans Act, etc.). The result at the service level are home care programs that are fragmented and have need for coordination and communication structures that link these entitlement and grants-in-aid programs together. This then creates a need for nondirect service staff who have titles such as "Coordinator," and "Planner," and "Programmer" while the real need is for professional and nonprofessional staff to give service in the homes. Money must be better targeted so that it does not dribble down to nothing by the time it reaches the level of unmet needs of senior families and individuals.

As implied previously, there is a great need for an adequate core of trained, committed personnel to provide on-line service in community based systems of home care. The best paid and best trained personnel should be the ones who work with the senior families and individuals in the homes. Home care is destined toward a poor evaluation if seniors are treated superficially and inappropriately at home in ways similar to reported cases of maltreatment and abuse of seniors in some institutional settings.

### SUMMARY

Mr. Chairman, I have tried to be brief in my statement and will summarize now for the Project LIFE Homecare program:

1. We believe that home care based on a social work construct similar to Project LIFE's, a Title IIIB program, is cost-effective. Not only does it help prevent institutionalization of those seniors who are enrolled in services and treatment, but it provides ancillary, advocacy and remedial roles that tend to save society millions of dollars while at the same time protecting the lives of numerous seniors.
2. We believe that home care has a positive efffect on seniors by enhancing their feeling of independence and dignity.
3. We believe that inadequate funding of home care due to a federal bias towards institutional policies is a real problem that must be solved if seniors are to receive equitable direct treatment at home.
4. We believe that much more must be done to make home care policies more consistent and fair so that increased money can be targeted toward and quality care given to those senior families and individuals for whom home based care is found to be the best alternative; not because it is cheapest but because it is the best for the persons who have unmet needs.

### ATTACHMENT A--BRIEF DESCRIPTION OF THE PROJECT LIFE HOMECARE PROGRAM

Project LIFE was created in 1975 as a result of community demands. Many hundreds of senior families and individuals have benefited from an array of services since that time. The program's current staffing pattern consists of a professionally trained Director, a licensed professionally trained Supervisor, two certified Masters of Social Work professional and one Bachelor's Degreed social worker. These workers provide case management and case assistance social services that include referral, entitlement's counseling (a form of advocacy), information, supportive contact, outreach, assessment, reassessment and follow-up. Four trained Homecare Workers provide in-home envirnmental maintenance services such as light cleaning, light shopping, meal preparation, payment of bills and rent; banking, laundry preparation. An Escort Worker links seniors to local social and public service and medical facilities and organizations. A core of Housekeepers also provide in-home services. Both social workers and paraprofessionals have bilingual staff on line.

Project LIFE is linked to existing local hospitals, the Social Security office, the local Department of Social Services, nonprofit service agencies such as Visiting Nurses and the American Red Cross in addition to any other relevant service organization for the elderly.

The program is funded by Title IIIB of the Older Americans Act with some New York State funds allocated through the Community Services for the Elderly (CSE) program. The catchment area extends from East 96th Street North to 138th Stret; from Fifth Avenu to the East River, an area called East Harlem.

To the extent that East Harlem's senior populations are highly diverse, the seniors who use Project LIFE's in-home services are representative of this diversity. Most of the users of in-home services are Hispanic and Black women who are widowed recipients of Social Security and who live alone, having a mean age of 74.2 years. About 10% of the users are White women who have similar descriptions with the exception of a higher mean age of 75.1 years.

Interestingly, 34% of the users are men who are characteristically similar to women by race. The men have a higher mean age than women, 75.1 years.

Nearly all of these seniors have one or more social and health-related problems in the areas of hypertension, diabetes, glaucoma, arthritis, heart disease, rheumatism and cancer.

These seniors come from each area within East Harlem and they are mostly referred for service by community agencies (45%) and hospitals (24%). Other seniors are referred by friends and relatives, private individuals, public agencies and some are self-referred.

Some examples of social problems found in Project LIFE's caseload include phobias, anxieties, depressions, inabilities to sustain relationships with family members; grief, low self-esteem, inability to adapt to aging, social isolation and segregation from mainstream community life.

## ATTACHMENT B—BRIEF DESCRIPTION OF THE ELDERLY POPULATIONS IN EAST HARLEM

East Harlem, New York, is found in Community District Number 11 which is located on the Northern end of upper Manhattan. The Census Bureau reports that in 1980 about six percent (more than 16,000) of the total 60+ populations in Manhattan lived in East Harlem.

East Harlem's senior populations are diverse by ethnicity, race, culture, health status, longevity, language patterns, living arrangements, family composition, gender, income and other factors. From age 60, women outnumber men by nearly two to one; by age 75 women strongly outnumber men by the two to one proportion. With increasing age, more than one-half of East Harlem's seniors live along. Widowhood begins relatively early for the community's Hispanic and Black elderly due to a much shorter life-span of Hispanic and Black men. In 1983, the most frequently reported causes of senior mortality in the area were malignant neoplasms and cardiovascular renal disease.

Where possible, some seniors continue to live with their spouses (about 20%) and with other relatives (about 15%) in types of extended families. The extended family composition also includes a few seniors who live with nonrelatives. In East Harlem a very few seniors (about 5%) reside in community-based institutions and ever fewer benefit from congregate living arrangements due to scarcity of such programming.

A quick glimpse of East Harlem's average Social Security income shows that less than $4,000 per annum is the norm for the senior community. Many of East Harlem's seniors, especially widows, have incomes that rank at or below the poverty level, and a sizeable number of these populations is too disabled to access services by use of public transportation. Today, most of East Harlem's seniors are extracted from a major ethnic or racial group (Hispanic and Black; White ethnic groups as well).

Adequate housing and social services are problematic for seniors who are in the grips of crisis.

## ATTACHMENT C—CASE EXAMPLE

Frequently, some of the rules, regulations and procedures that define home care tend to conflict, sometimes overlap and duplicate, sometimes help, and sometimes lead to catastrophic consequences for seniors in crisis. Take this case for example.

An 84 year old man with limited mobility was hospitalized for a planned brief stay. The home care program was maintaining his public housing residence in anticipation of his return. The man was doing relatively well with his $550 per month Social Security check in that his rent cost $101 per month. He was able to pay for his Medicare card and the deductibles and copayments related to it and the medical treatment that he was undergoing. Without communicating with the home care program, the hospital negotiated placement into a nursing home in another county because this man had only 12 hour home attendant services, which Medicaid paid for. No effort was made on the part of the institution to seek to expand home attendant services in the home with the use of visits under Medicare and more hours under Medicaid.

If for any reason at all the nursing home fails this man, the likelihood is that he will end up on the street, having lost his residence, having been removed from his community of birth and having virtually no say in his being disposed to institutional treatment.

This case is also instructive as to how communities lose per capita income when institutions place long term community residents into other institutions in other districts or counties.

Dr. Trent. Ms. Hussey would like to speak about the services that she has received under us.

## STATEMENT OF ETHEL HUSSEY

Ms. Hussey. I want to tell you why home care is important to me. It made me a member of the community because if I did not have home care I would sit at home. I use my person coming in to help me to shop.

I am a diabetic, so I must be careful of what I am buying and can't always ask the clerk in a store what each thing contains. But when I have my personal home care worker beside me I feel secure. I feel as though I am mistress of my own home.

It encourages me not to be a wallflower, and I want to tell you, home care is enabling me to be independent. I can care for my personal business.

I am given escort service if I have to go somewhere that I can't arrange myself. You know, you were talking about hospitals, and recently I was in a hospital for cancer. Thank God, I think they found it all and got it out.

But anyway, I was asked if I would like to go to a nursing home afterwards, and I said, no, and this was my reason, and I think it is important. Going to the hospital and going through certain experiences were adjustments.

If I had gone to a nursing home it would have been another adjustment. Coming home after those two places would have been even another adjustment.

So, my decision was to come home where I know my apartment, where I can maintain myself with some help from Medicare. Medicare only gave me 20 hours a week, and there is where I think things should change, because it ought to be according to the person's need.

That meant only 4 hours a day with me and the rest of the day I would be left alone. I thought that was a little silly, but you know—anyway, you know, I have to go back to my life.

Project LIFE means much more than someone going into the home; it means belonging to something. We have excursions a couple times a year where we meet different people in a group and it is a way of saying hello.

I happen to live in New York. I am the only member of the family living in New York. I do live alone.

Even a little care package a couple times a year—so, it doesn't matter so much about what is in the package, it means being remembered.

I don't know what else I can add—probably a lot.

Mr. Biaggi. You are given 4 hours a day now?

Ms. Hussey. That is from Medicare.

Now, under home care, under Project LIFE, it is 2 hours a week. I wish it could be more because we all have different needs.

Mr. Biaggi. What more could they be doing for you?

Ms. Hussey. Let me think. I must tell you something funny. Before I had Project LIFE help me with shopping I would do my own shopping, and, of course, I was told by clerks—well, twice I remember distinctly, one, we can't help you, we are busy right now.

He said to call them up on the phone because they can attend to me much faster than my being there. You know, it gave me the feeling, it is my money I want to spend it, and I was a second-class citizen.

You know how I felt? I cried literally, because I was trying to be independent and this is what I got.

Mr. Biaggi. Are you able to function in your house?

Ms. Hussey. Yes; somewhat. I do need someone coming in to—well, to correct me, for instance, is this blouse clean or dirty, does my floor look neat. I take care of it, but I can skip places.

Mr. Biaggi. Are you unsighted?

Ms. Hussey. Yes. I don't see at all.

But the funny thing I wanted to tell you, at times I go into stores, and it creates problems. I buy things, and I have taken home things, I don't know whether they belong to me or not, did I pay for them, was I cheated?

That I need help in, too. When someone is with me she looks at the bills. One time I opened a package, it didn't belong to me, but it was in my car—at least I think it belonged to me, and I had to taste it to know what it was. It was milk bone.

Anyway, I think home care is great. I think we could do much more. Each person may need a different amount of time.

Also, with my mail, if I don't know what it is I have to ask the home care worker to read it. I have neighbors, and I told you I recently came out of the hospital a month ago with surgery. You talk about neighbors, not one person knocked on my door to say do you need anything, but Project LIFE called me in the hospital to find out how I was doing, when I was going to come home. It is Project LIFE that covers me, so I am very greatful.

Mr. Biaggi. Ms. Swinton?

## STATEMENT OF CONSTANCE SWINTON

Ms. Swinton. I was asked to come here to tell just what Project LIFE means to me. I ask you to be very patient with me because I may not seem to be explaining myself very well. This is what I wanted to say.

I got sick about 9 months ago and my eyes began to go bad, and now I notice they are becoming worse and worse and I can bearly see. I want to say that if it hadn't been for Project LIFE I would be very, very uncomfortable.

But the thing that I want to impress on you all, I only get 2 hours a week, and that can do me very, very little good. My daughter, she works and she comes around sometimes, I see her once a week or sometimes a couple hours in the day, but I am just left alone.

I am going out in the street, I need somebody, not to support me, but just to give me that confidence of having somebody with me.

Mr. Biaggi. If you were in a nursing home you would have company; would you like to go to a nursing home?

Ms. Swinton. No; I would rather be in my own home because it is more comfortable for me.

I know my surroundings and can adjust myself and I feel more independent. If I got into a nursing home I would be completly dependent on the people there.

The hospital, I pay for my clinic fee, $11, and I buy my medicine, sometimes it runs to $42. I would like to see Medicare make it so I could get my medicine at a much cheaper rate or maybe pay it for me, that would help me a lot.

Mr. Biaggi. But you are a whole lot better at home?

Ms. Swinton. I am better at home but I would like to get Project LIFE to give me more assistance.

I try to cook. I can't go into the street without assistance and this makes me feel independent when they come in and do a little something for me.

So if it is possible I could get more help there, somebody to help me, it makes me feel more independent.

Mr. Biaggi. Thank you.

Ms. Husney. May I add something?

Mr. Biaggi. Yes, Ma'am.

Ms. Husney. The trend today is for the older person. Longevity is here. What is the good of longevity if we can't be useful to ourselves.

The word is encouragement. The word is dignity; and I think that is great.

Mr. Biaggi. Dominigo Mendez.

## STATEMENT OF DOMINIGO MENDEZ

[Through a translator.]

Translator. He speaks little English, and he wants me to speak for him.

He says, he needs housekeeper services and escort services because due to his health condition he is limited to manage with his house chores. He receives a housekeeper.

He has arthritis and a liver condition, cirrohosis of the liver. He participates in recreational activities, but he needs help because he lives alone and he doesn't have family to help him.

Mr. Biaggi. Does he like—would he like to go to a nursing home?

Translator. He always said to me that he wants to be independent and he doesn't like to be in a nursing home even when his health condition became worse.

I asked him, does he want nursing home services, and he refuses, because he wants to manage for himself and he wants Project Life services because he feels better.

Mr. Biaggi. How many hours a week does he get.

Translator. Two hours a week.

Dr. Trent. May I clarify that a little bit?

Certainly we felt that home care is unfunded. There is no balance. We have balanced the 2 hours schedule over the years at community demand.

We tried a 3-hour scheme, we tried a 4-hour scheme. We weren't able to serve enough people with the money that came through title III-B.

What we found is that 2 hours per person, once per week, with more monitoring by social workers, and with supervisory monitoring, we can serve three people per day everyday for each work week.

We have 10 workers, so that permits us to service 80 to 100 people in terms of home services per month. That is juggling, and there is a demand for increased services but there has to be fairness throughout the system and we try to equalize it that way.

Mr. Biaggi. Who funds this?

Dr. Trent. The Department for the Aging.

May I make one more comment—I have an attitude about the use of aides. I did a citywide survey for my dissertation that spoke to the question of effects of supervision on home care worker performance, and we find that in title III-B a sample of 150 home care workers, we found a very high degree of commitment, very, very high performance in terms of numbers of days on the job, no alcohol and drug addiction.

We find that there is a relationship between the person who is receiving care and the person who is giving it that is very important.

Mr. Biaggi. You are seeing the same people all the time?

Dr. Trent. We try to be consistent. These are community people with some relationship to people in the community.

Mr. Biaggi. How do you select your clients?

Dr. Trent. Very carefully. Basically the supervisor who came out of the health and hospital system will conduct interviews.

We do very careful screening, and so forth. Most of our permanent people, we have trained them in some way.

Mr. Biaggi. I don't mean the employees; I am talking about——

Dr. Trent. Well, that is a question relating to targeting services. The regulations that Government puts down are that we shouldn't duplicate what Medicaid does, and we don't. We may complement that program in some ways.

So basically the type of person that we are serving might be what they call the downwardly mobile person, the catastrophic person who has had incidents where medical expenses have taken away most of his or her resources.

One person here receives a limited amount of Social Security and has to pay most of her medical bills herself. She is that type of marginal person that we are dealing with.

Mr. Biaggi. Ms. Swinton?

Ms. Swinton. I wanted to say, too, in going to the hospital I find my bills so expensive. During the time I worked I tried to save a little money to sort of look forward for this day and have something to sort of carry on that I wouldn't be depending on the city.

I have always been a poor but independent person, and many times I need help. Project LIFE is willing to help me, but they haven't got the help, and I feel like if I get the help I need it will help me to live a better life. I don't have to have somebody every day, but I have to have somebody more often than the 2 hours a week.

Mr. BIAGGI. I appreciate that, Ms. Swinton, and I respect your sense of independence, and I appreciate your concern, too.

Ms. SWINTON. Thank you.

Mr. BIAGGI. We have been trying, on a Government level, we have been trying for years. We have improved substantially over the years but we have got a considerable distance to go.

Ms. SWINTON. Thank you.

Mr. BIAGGI. Joan Marren.

## STATEMENT OF JOAN MARREN, DIRECTOR OF HOME CARE, MOUNT SINIAI HOSPITAL

Ms. MARREN. Thank you for the opportunity to present testimony today. I am summarizing my testimony.

I am the director of home care here at Mount Sinai Hospital. We are a certified home health agency, which is hospital based.

Most of the discussion that I have heard so far today has dealt with looking at the cost-effectiveness——

Mr. BIAGGI. May I interrupt you for a moment?

Dr. Trent, your people you serve may want to leave, and you may want to leave, but I would like to make one statement.

First I want to thank you and your clients for coming down. We have heard from expert witnesses, and all their contributions have been very, very substantial, but what we heard from your three clients is very simple, but very critical.

Home care works. Home care works and they need more of it, they need more funding, and that is what it--that is what we are trying to get. Our impression over the years has been that it is difficult for home care to move in because the nursing homes and the various institutions have been in place for a long time, and we have more than 90 percent of the budget, and for them to encroach on their funding is difficult, so we require to have additional fund provided so we can target those funds directly for home care.

Your three clients said it simply but most eloquently and I want to thank you. You are free to leave if you like.

You are free to remain if you like, whichever.

Thank you very much.

Ms. MARREN. A lot of the testimony that was offered dealt with the cost-effectiveness of home care in situations where Medicaid is available for coverage to clients. The population that we deal with, being a hospital based home health agency, our population is primarily drawn from the in-patient areas, and we are, therefore, engaged in providing care primarily to Medicare clients.

For our clients very often the main issue is not so much the cost-effectiveness of home care versus institutional care, but whether or not home care is even an option for these clients, because there are so many people who fall between the cracks, so to speak, who are "too rich," quote unquote, to be eligible for Medicaid, but too poor really to be able to afford the kind of care that they need.

Over the last several years we have encountered increasing difficulty in attempting to service our clients. Medicare has really become a benefit program which focuses entirely on acute episodic illness requiring hospitalization and skilled medical intervention.

Whatever home care services are provided by Medicare, they are tied to a acute episodes of illness requiring short-term skilled care in the home. We find that this method of home care services often meets the needs of the young, relatively well elderly, with newly diagnosed diseases.

However, as a result of advancing medical technology, we are finding that—and methods of diagnosing and treatment we find a gross number of very elderly with chronic illness increasingly debilitated by their illness and in need of long-term care. Their needs are either custodial or their needs are what we would refer to as high-technology services, such as a patient who might be on a respirator requiring periodic suction during the day or night.

In either case both groups of patients require long-term care which is not covered by Medicare, either because of the low level of care that is required or because of the intensity of the care that is required, those services are not covered at home.

As far as we can see they are sort of a new generation of chronicly ill that have been saved by the system but are left with no options for ongoing care within it. We find the problems have been exacerbated by developments within the health care system over the past years.

Reducing medical expenditures by the hospitals have led, at least we find, to greatly increased expectations for the availability and the accessibility of home care services. Elderly patients are being discharged quicker and sicker to a home care system that we find often inadequately prepared to manage them.

Most hospital based programs, our own included, New York Hospital, most of them in the metropolitan area are experiencing increasing frequency of hospital readmission from their home care programs. Waiting periods for home health aides and therapy services are frequently lengthy.

It is not unusual in certain areas, particularly those that are different in terms of reaching for public transportation, or that are generally considered unsafe in the city, that a person might wait up to 2 weeks for a home health aide or a physical therapist.

Adequate numbers of prepared staff to meet the demands of the sicker population in the community have not been available, and attempts that the hospitals have been experiencing their financial crunch and pushing for earlier discharge home health agencies have been experiencing also pressure to cut back on Medicare services.

Two years ago the issue and customary number of home health aide hours was reinterpreted from 100 to 40 hours per month requiring employers to submit extensive documentation on bills. Home bound status has been interpreted and monitored more rigidly.

Intermittent care has been reinterpreted to call into question coverage of daily visits to clients, a 20-percent copay has been put in position for home equipment. New cost caps for home care services have been put into effect which eliminate an agency's ability to aggregate cost and actually lower our reimbursement rate for home care visits over the next 3 years.

In addition, documentation is now required which essentially places every employer on 100 percent prepayment review for every visit rendered to every Medicare client. The environment of service provided to Medicare clients could probably best be described as sort of a sutle form of harassment.

At times the objective seems to be that ultimately it will become so difficult to service the clients that you will chose not to. Clearly the intent is not to take saving from one area such as those obtained through DRG's and institutional care and to build services in another.

We are in home care at least as far as Medicare is concerned experiencing as many pressures and as many cutbacks as we find the hospitals are. Obviously, we don't feel that this will result in expansion of home care services and at a time when hospitals are experiencing the most severe cutbacks that they have seen in years, there can't be—and are looking at home care for alternatives—there can't be retrenchment within the system, as well as if a reasonable level of quality health care is to be available to the elderly.

We think that the restrictive cost caps newly in place must be withdrawn by legislative mandate if necessary and there is currently legislation pending to require that there not be a cut or a reduction in the per visit reimbursement for home health agency visits as has been proposed by HCFA. Efforts to impose visit copay must be withdrawn permanently.

We find that sometimes these things are withdrawn but will surface at some time in the future. Efforts to train people to provide home care services must be supported.

Legislators would do well to undertake educational campaigns among the elderly constituents to correct misconceptions regarding care services. There is a recent study done by AARP of a thousand persons in the United States and it was astounding to find how many elderly people believed that if they should require nursing home placement or long-term care that their Medicare coverage would pay for it, and there is nothing futher from the truth. But that in general they have a lot of misconceptions about what is and what is not available to them.

Efforts to organize legislative and citizens watchdog groups to monitor efforts to reduce Medicare expenditures for home care should also be established. We think on a larger public policy issue that the Medicare system itself requires some close examination and questioning of its priorities.

As we find that the numbers of elderly with chronic diseases and long-term care needs increase, should not the public health care dollar be directed toward the area of greatest public health are need.

I don't think it is possible to significantly improve the health care service to the elderly while continuing to lower our national health bill. There may be a fair amount of support within the public at large for additional taxes, but I don't believe that the public is willing to support a system of unlimited health care.

And the kind of needs that we see evolving within the population that is not considered the poor, and is really without care, really, in many ways are unlimited. In the absence of substantial additional dollars for health care, shifts will be necessary in present expenditures and priorities.

In their article "Hospital Cost Control, a Bitter Pill to Swallow," in the March-April 1985 Harvard Business Review, it is stated that the rapid growth of outlays for hospital care has become a problem because of the interaction between the method of paying for it and the distorted rate of scientific advance. Clearly, the growth of spending flows from the never ending appearance of new modes of diagnose and treatment.

Andrew Stein noted in his New York Times article on Medicare that every other advanced industrial democracy has managed to extend comprehensive health coverage to its elderly and has done a far better job of controlling health inflation.

Most however, have done that by making conscious public policy choices regarding the development and/or the availability of medical technology and directing finite resources to the areas of greatest public health benefit so that the shift away from emphasis on acute episodic care toward the chronicly ill will require some difficult choices.

Our preference would be that those shifts begin to occur among people like ourselves at this point. One of the biggest problems that we have with Medicare at the present time in terms of its definitions, say, of skilled care, is that they are really bureacratic defintions, and they are very much unrelated to, perhaps, what a professional estimate might be to provide a certain level of care, and also unrelated necessarily to the real needs of that person.

And one—at least one of my major concerns is that if we don't begin to make these kinds of decisions that will allow us to move, and to shift toward addressing the needs of the growing population of people who require long-term care, away from the emphasis on acute care, that those kinds of decisions, and ultimatley, rationing will be made for us.

And like the issues related to Medicare and its defintion of skilled care, we will ultimately feel that service is dictated for us rather than having some input into how those services should be distributed and rendered to people. Thank you.

Mr. BIAGGI. Thank you for your testimony. I won't fret too much about the abundance of input, because you can be assured that folks like yourself and part of the whole network throughout the country are ever on the alert, and they have been very helpful to us.

Ms. MARREN. Especially more recently with the National Association for Home Care monitoring a lot of what takes place with HCFA. The problem with that, I find, at least, is that you spend so much of your energy watching out on what is happening that your creative energy in terms of delivering service to people is often very much drained.

Mr. BIAGGI. That is the life we live in. We do that ourselves.

Our days are long days. We like to be positive and constructive, but on the other side we must serve as watchdogs. Executive agencies, sometimes I wondered whether or not they are part of our whole national undertaking, whether we don't have some people who dislike people in those areas. It is a difference in philosophy.

There are people who don't think that government should be in people's business. I am not going to make any comment on that, but that is what we have to monitor.

We have been doing a pretty good job. In some areas we have been decidedly successful.

In other areas we have had a moderate degree of success and, of course, we have losers on occasion, but not because we haven't been alert. I don't mean simply the Congress, I mean all of us who are concerned.

The minute something rears its ugly head the signal goes out all over the Nation. There is a clairon call, and response, and pressures and calls. We have hearings. We focus attention on it, and we have had agencies pull back regulations, taken them out completley or modified them; or delayed them, and sometimes they withdraw them as a result of the initial outrage and then try to reintroduce them after the furor has subsided.

We are alert, not only as Members of the Congress and our staffs, but people like yourselves and the organizations out there. They do a very, very professional and expert job in this area, and the bureaucrats understand it.

The minute they pose a proposition, or even talk about it that is counterproductive or contrary to our perspective, they can expect a deluge; and they do.

I know what you are saying, you would like to live in the ideal world, where that is in place, let's create something else, but this is the world we live in.

Ms. MARREN. Well, I do think, though, that some of the real questions about priorities within the Medicare system and the shifting of the resources of that system need to be addressed, or else there wouldn't be resources to address the needs of long-term care patients who are never going to be eligible for Medicare but have long-term needs.

Mr. BIAGGI. I think we will have a problem. I think we will have a problem with long-term needs and home health care. I really think so; because it will be a question of getting more money.

In this atmosphere, that is not really all that doable. This atmosphere has to change.

I posed a question to Dr. Butler, what I thought the institutions would resent or impose an obstruction, he thought not. I am not as sanguine about it as he is. The minute you start to encroach on their dollars, they are just as alert as we are, only they have even a greater interest.

There is money to keep themselves alive and flourishing, and they have a very professional lobbyists in every area, right within the bureaucracy. They have people that are sympathetic with the institutions and within the different agencies. So I am not so sure it is going to be as easy as Dr. Butler said.

I think clearly we have to present a blueprint for the future, No. 1; and then try to implement it piecemeal, or if we can, and that would be the way. You know, we can, as a result of experience, I think a piecemeal development would be what we expect.

We could layout the blueprint and then try to implement it a little bit at a time. But that is the problem.

Tom, do you have any questions?

Dr. Sencer.

## STATEMENT OF DR. WALTER SENCER, ATTENDING NEUROLOGIST, MOUNT SINAI HOSPITAL AND MEDICAL CENTER

Dr. Sencer. I have been listening to all this and nobody is arguing. I want to underscore what was said by Dr. Marren. I want to repersent the middle class.

I did't know that Project LIFE would bring people here, because I have a person on Guggenheim 4, who should have been here. This is a lady in her fifties who desparately wants her husband to come home. He is very sick, much sicker than what you have seen.

She doesn't care. She wants him home. I think many, many people in the United States want their sick elderly relatives home. You haven't heard from these people. The patient is maybe so sick he doesn't even know where he wants to be home or not. The relatives want him home.

Mr. Biaggi. Why would they want him home?

Dr. Sencer. They love and respect him.

Mr. Biaggi. They believe he will get better care at home?

Dr. Sencer. They know he will get better care at home. The problem is that this lady has gone through thousands of dollars now because they are running out of insurance, Medicare doesn't cover. To go home, it is mind boggling.

Mr. Biaggi. Well why——

Dr. Sencer. There is no money for home care——

Mr. Biaggi. She would need some assistance also?

Dr. Sencer. She doesn't want him in a nursing home. Nursing homes can give this kind of skilled nursing care.

But there are many people, stroke victims, who need more than just assistance, they need care. And there is no money available from the Government for those people, and I think this is very, very important.

If you are very wealthy you can do it. Park Avenue has many people living at home with their loving children. It costs a bloody fortune. They can afford it.

But middle America, no way, and I think it is sad. Now, what goes on in our home care program, I hear it every week. That is why we had this discussion.

It never stops. People are being hurt. Without their wishes they have to send their loved ones to nursing homes, which are fine, but they don't want to.

America doesn't want nursing homes.

Mr. Biaggi. Mr. Manton.

Mr. Manton. Mr. Chairman, I think we have had a very fruitful hearing here today.

I don't have any questions but I think the transcript of the hearing today will be very beneficial for our study and for perhaps some legislative suggestions coming from it.

I thank you for having the hearing. It is a very important subject.

Mr. Biaggi. Thank you for being here, Dr. Sencer.

Joan Marren, Thank you very much.

The hearing is adjourned.

[Whereupon, at 12:30 p.m., the hearing was adjourned.]

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